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Young People's Experiences and Expectations of Successful Renal Transplants

And Clinical Research Portfolio

Volume 1

(Volume 2 bound separately)

Evelyn Watson

*Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology
(D.Clin.Psy)*

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DECLARATION OF ORIGINALITY



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Declaration of Originality Form

Name: EVELYN WATSON

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Course Name: DOCTORATE IN CLINICAL PSYCHOLOGY

Assignment Number/Name: YOUNG PEOPLE'S EXPERIENCES AND EXPECTATIONS OF
SUCCESSFUL RENAL TRANSPLANTS

AND CLINICAL RESEARCH PORTFOLIO

I confirm that this assignment is my own work and that I have:

Read and understood the guidance on plagiarism in the Doctorate in Clinical Psychology Programme Handbook, including the University of Glasgow Statement on Plagiarism ☐

Clearly referenced, in both the text and the bibliography or references, **all sources** used in the work ☐

Fully referenced (including page numbers) and used inverted commas for **all text quoted** from books, journals, web etc. (Please check the section on referencing in the 'Guide to Writing Essays & Reports' appendix of the Graduate School Research Training Programme handbook.) ☐

Provided the sources for all tables, figures, data etc. that are not my own work ☐

Not made use of the work of any other student(s) past or present without acknowledgement. This includes any of my own work, that has been previously, or concurrently, submitted for assessment, either at this or any other educational institution, including school (see overleaf at 31.2) ☐

Not sought or used the services of any professional agencies to produce this work ☐

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Signature.....Date.....

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First, and foremost, I would like to say thank you to the young people who gave their time to participate in my major research project. It was a privilege to have met you and I feel honoured that you were willing to share your experiences of kidney transplantation with me. You have taught me so much.

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CHAPTER 1: Systematic Review

The Relationship Between Patients' Pre-transplant Expectations and Their Post-transplant Outcomes: A Systematic Review

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ABSTRACT

Background: When deliberating whether to accept a medical treatment, it seems patients might base their decision upon how they predict the treatment will affect their future health status, psychological wellbeing and social functioning. Organ and tissue transplantation are increasingly common interventions for the treatment of chronic illnesses. As with other medical treatments, the effect of pre-transplant expectations on post-transplant outcomes is uncertain. Patients' pre-transplant expectations may have no impact on their post-transplant outcomes (in terms of their physical health status and psychosocial adjustment); although it is also possible that they could be instrumental in determining the results patients obtain. A greater understanding of whether patients' pre-transplant expectations are related to their post-transplant outcomes could be invaluable in terms of treatment planning.

Objectives: The effect of patients' pre-transplant expectations on their post-transplant outcomes is unknown. This review was therefore conducted to collate and appraise the existing literature pertaining to this relationship, and aimed to answer the question "do patients' pre-transplant expectations impact their post-transplant outcomes (physical health status and psychosocial adjustment)?".

Method: A systematic literature search was carried out to identify articles that investigated how patients' expectations of organ and tissue transplantation relate to their post-transplant outcomes. The following databases were used to identify relevant studies using a systematic search strategy: MEDLINE, EMBASE, Psychology and Behavioural Sciences Collection, PsychInfo, CINAHL, Web of Knowledge and Cochrane Database. The identified articles were then screened against a priori inclusion criteria and their quality evaluated using the Crowe Critical Appraisal Tool (CCAT).

Results: Five studies met the review's inclusion criteria. Two studies were rated as 'Good Quality' (40%), two as 'Moderate Quality' (40%), and one as 'Poor Quality' (20%). These studies offered conflicting findings pertaining to the relationship between patients' pre-transplant expectations and their post-transplant outcomes (physical health status and psychosocial wellbeing). These contradictory results make it hard to draw definitive conclusions about the nature of this relationship, and might be explained by the differences in these studies' quality or by the complexity of comparing investigations that have employed different methodological approaches.

Conclusion: Although some of the papers included in the review offered evidence of a relationship between patients' pre-transplant expectations and their post-transplant outcomes, this finding was not consistently replicated across studies and in general the previous research exploring this relationship was not found to be robust. It must be concluded that the existing evidence remains inconclusive at present and that further research is needed to gain greater understanding of the relationship between patients' pre-transplant expectations and their post-transplant outcomes.

INTRODUCTION

When deliberating whether to accept a medical treatment, it seems patients might base their decision upon how they predict the treatment will affect their future health status, psychological wellbeing and social functioning (1). These predictions are referred to as patients' pre-treatment expectations (1). One current uncertainty is whether patients' pre-treatment expectations have the power to influence their post-treatment outcomes. The concept of "post-treatment outcomes" is broad and its operational definition tends to vary across studies. It is typically used in reference to patients' physical health status (e.g. survival, reduction in illness symptoms) and psychosocial adjustment (e.g. quality of life, experience of low mood or anxiety) following medical treatments (1).

A number of previous studies have found that patients' possession of positive pre-treatment expectations increases their likelihood of obtaining more favourable physical health outcomes following different types of medical interventions, for example hip/knee arthroplasty and surgery to treat breast cancer (2; 3; 4). It has been argued that positive pre-treatment expectations could operate to promote better physical health outcomes in a number of ways. For example, by triggering a beneficial physiologic response within patients or by increasing patients' motivation to engage with medical advice (5).

Nonetheless, it has also been argued that positive pre-treatment expectations could sometimes operate to render patients more vulnerable to the development of post-treatment psychological difficulties in certain circumstances (6). Cognitive biases are known to operate in human decision-making and research shows that they often lead people to overestimate the effect life events will exert upon their emotional wellbeing (7; 8). For example, people generally think that having a disability would result in a significantly lower quality of life than is typically reported by people who actually have a disability (9). This is known as the "impact bias" (8). In medical situations the operation of the impact bias could result in patients holding unrealistically positive or negative expectations about their forthcoming medical interventions. If patients hold unrealistically positive pre-treatment expectations it would place them at increased risk of foreseeing greater improvements in their health status and quality of life than they would subsequently experience after having their medical procedure (10). This discrepancy could create disillusionment, dissatisfaction, and a state of cognitive dissonance that might negatively impact patients' psychological adjustment and willingness to adhere with later medical advice (11; 12). For example if a patient expects "a return to normal" after receiving a medical treatment and this does not occur, they might suffer higher levels of emotional distress than a patient who experienced the same tangible outcomes but who never

anticipated highly successful results (11). From this perspective positive pre-treatment expectations could have the power to exert a negative impact on patients' later post-treatment outcomes (11).

Patients' possession of negative pre-treatment expectations could also be highly important. For example, one previous investigation offered results suggesting that negative expectations about the likely benefit of pain medications decreases their subsequent analgesic effectiveness (13). On the other hand, it has also been proposed that negative pre-treatment expectations could also increase the likelihood of positive treatment outcomes. For example if patients' expectations were very low before treatment then even slight improvements may be perceived as beyond previous hopes and result in higher levels of treatment satisfaction and emotional wellbeing (14).

The Role of Expectations in Transplantation Surgery

Organ and tissue transplantation are increasingly common interventions for the treatment of chronic illnesses (15). As with other medical treatments, the effect of pre-transplant expectations on post-transplant outcomes is uncertain (16). Patients' pre-transplant expectations may have no influence on their post-transplant outcomes; but it is also possible that they could play an instrumental role in determining the results that patients obtain (their post-transplant physical health status and psychosocial adjustment). A greater understanding of whether patients' pre-transplant expectations are related to their post-transplant outcomes could be invaluable in terms of treatment planning to optimise transplant results. For example, if positive pre-transplant expectations were found to directly heighten the long-term success of patients' transplants then interventions could be developed to help patients build, bolster and maintain positive pre-transplant beliefs about the likely outcomes of their transplant surgery (16). Nonetheless it would be equally helpful to ascertain whether pre-transplant expectations actually have no impact upon post-transplant results (16). For instance, healthcare staff sometimes describe a fear of talking to patients about particular medical risks in case this diminishes patients' positive outlook and desire to live (17; 18; 19). This is an ethical dilemma given the important ramifications this might have on ensuring patients' informed consent to treatment (11). Clarification that pre-transplant expectations are of no consequence to long-term post-transplant outcomes, could improve medical staff's communication with patients by alleviating any concerns they might have that discussing medical risks could be damaging (11).

Systematic Review Rationale and Objective

The effect of patients' pre-transplant expectations on their post-transplant outcomes is unknown. Nonetheless, having a greater understanding of this relationship could be of significant clinical utility. This review was therefore conducted to collate and appraise the existing literature pertaining to this relationship, and aimed to answer the question "do patients' pre-transplant expectations impact their post-transplant outcomes (physical health status and psychosocial adjustment)?".

METHOD

Search Strategy

A systematic literature search was carried out on the 2nd June 2013 using electronic bibliographic databases: MEDLINE, EMBASE, Psychology and Behavioural Sciences Collection, PsychInfo, CINAHL, Web of Knowledge and Cochrane. Mesh headings such as “transplant*” were used to search the databases in conjunction with Boolean operators (see Appendix 3 for full search terms). No date range limit was applied to the individual searches. The titles and abstracts of the resulting papers were screened to identify relevant studies. Electronic database functions were used to find additional papers that cited, or were similar to, all of the studies identified as relevant. The reference sections of relevant articles were hand-searched to identify additional papers that met criteria for inclusion in the review. Figure 1 is a flow diagram that illustrates the article search strategy.

Eligibility Criteria

All articles returned in the systematic literature search were screened against the following eligibility criteria. Papers that did not meet these criteria were excluded from the review.

Types of studies: All studies had to explore the relationship between patients’ pre-transplant expectations and their post-transplant outcomes. All study designs were considered for inclusion in the review, except single case studies and those using qualitative methods of data analysis. All studies had to be published in a peer reviewed journal. Studies were excluded if they were not published in English. No publication date restrictions were imposed.

Types of participants: Participants who had received any type of organ or tissue transplant were considered. No age limits were applied.

| | |
|--|---|
| Types of pre-transplant expectations: | Studies had to include a measure of participants' pre-transplant expectations (about the likely impact of their transplant on their physical health or psychosocial adjustment post-transplant). No restrictions were placed upon the specific types of measurement tools employed. |
| Types of outcome measures: | Studies had to include a measure of participants' post-transplant physical health or psychosocial adjustment. No restrictions were placed upon the specific types of measurement tools employed. |

Quality Assessment and Data Extraction

The quality of the final studies included in the review was evaluated using the Crowe Critical Appraisal Tool (CCAT), which is detailed in Appendix 4 (20). The CCAT was selected because it has been shown to be a valid and reliable instrument for appraising health studies in a wide range of research designs (20). The CCAT assesses research studies across eight appraisal categories (*preliminaries; introduction; design; sampling; data collection; ethical matters; results; and discussion*). Each category is scored from 0 (lowest score) to 5 (highest score), following the guidelines outlined in the CCAT User Guide (20). No modifications were made to the CCAT as its user guide clearly states that any alterations, irrespective of how minor they may seem, could threaten the validity and reliability of the scores obtained. Nonetheless a key strength of the CCAT, in comparison to other critical appraisal tools, is that there is no need for modifications as it has been specifically designed to evaluate the methodological rigor of different kinds of study. For example, the CCAT User Guide states that each paper's research design must be evaluated on its own merits rather than some preconceived idea of a research design hierarchy or 'gold standard'. The CCAT User Guide reports that what is most important is that an appropriate research design has been chosen with regard to the specific research question being addressed.

Using the CCAT, and its user guide, each study was awarded a maximum raw score of 40 points. A percentage rating score was then calculated for each study from the raw score it had been awarded. Study quality was described as: '*Good Quality*' (representing a percentage score >75%); '*Moderate Quality*' (representing a percentage score 50-75%); or '*Poor Quality*' (representing a percentage score <50%).

To ensure reliability in each study's quality assessment rating all papers were reviewed by the primary researcher (EW) and, in addition, a Clinical Psychologist who was independent of the study. Inter-rater agreement of the studies' quality rating categories was 100%.

Data Synthesis

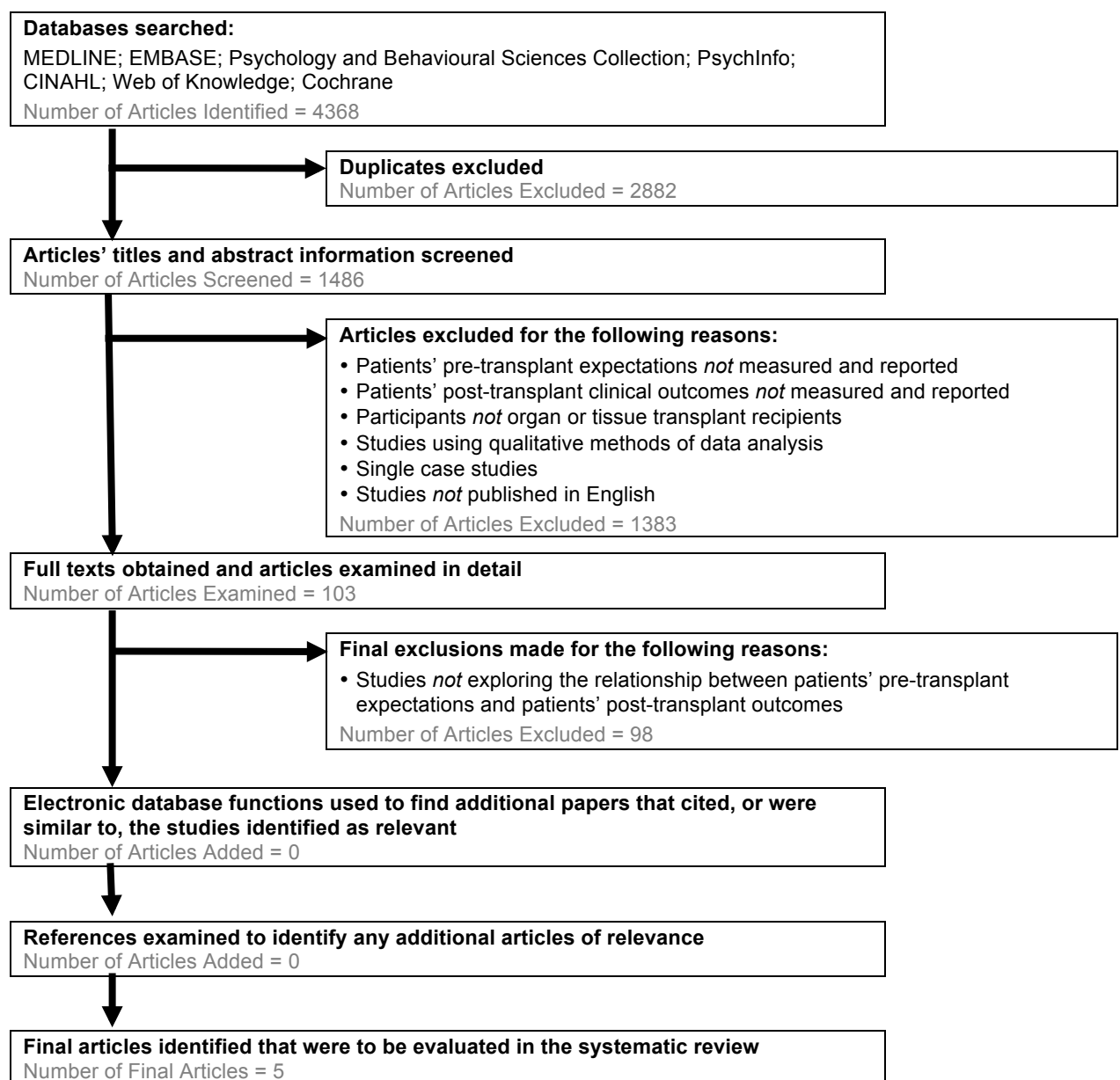
A small number of studies were identified for inclusion in this review and these varied markedly in terms of their designs, their participant characteristics, their operational definitions of "pre-transplant expectations", their chosen post-transplant outcome measures, and the statistical analyses that they employed. In addition to this considerable heterogeneity across studies, a risk of bias was also present within each individual study. The Cochrane guidelines on completing systematic reviews highlight that if the primary studies included in a review are clinically diverse then a meta-analysis can be meaningless, and obscure genuine difference in effects (21). In addition, the Cochrane guidelines also warn that meta-analyses can be misleading when their primary studies are at risk of bias; because a meta-analysis can act to compound such errors and produce a "wrong" result (21). For these reasons, it was concluded that a meta-analysis was not an appropriate method for synthesising the data in this systematic review.

A narrative synthesis was regarded as the most suitable approach for collating and appraising the findings of the studies included in this review. This is a qualitative approach to the synthesis of findings from multiple studies; that relies primarily on the use of words to summarise and explain results (22). The framework outlined by Popay et al. (2006) was used to guide the narrative synthesis (22). The four key elements of the process were: (a) theorizing around the possible relationship that might exist between patients' pre-transplant expectations and their post-transplant outcomes (to inform the systematic review objective/question; and decisions about what types of studies to include in the review); (b) developing a preliminary synthesis of the primary studies' findings (to describe patterns across their results); (c) exploring relationships in the data within and across studies (to consider factors that might explain any differences in the findings between the studies); and then, (d) assessing the quality of the studies and the overall robustness of the synthesis (to gauge the strength of the evidence that there might be a relationship between patients' pre-transplant expectations and their post-transplant outcomes).

RESULTS

Figure 1 describes the systematic literature search strategy that was employed with details of the number of papers that were identified, included, and excluded at each stage of the process. The initial database search identified 4368 papers of potential significance. After removing duplicates and carefully examining the remaining articles against the review's eligibility criteria a total of 5 studies remained: Andrykowski et al. (1995, 11), Holzner et al. (2001, 15), Lee et al. (2003, 16), Leedham et al. (1995, 1), and Pommer et al. (1985, 23).

Figure 1: Flow diagram of the systematic literature search strategy



Quality rating of studies

The final five studies included in the review are summarized in Appendix 5. Overall two were rated as 'Good Quality' (1; 16); two as 'Moderate Quality' (11; 15); and one as 'Poor Quality' (23). To enable useful interpretation of these studies it is necessary to consider their overall findings in respect of the relative strengths and weaknesses of their research methodologies (24). As such, the studies will be critically appraised in order of their quality rating with an overall interpretation of their findings being drawn at the end of this section.

Leedham et al. (1995, 1) examined whether pre-transplant expectations would predict patients' psychological adjustment and physical health following heart transplantation. This study's external validity was strengthened by its employment of consecutive sampling, although only one transplant centre was used during recruitment (25). One weakness was that the size of the recruited sample was not informed by a power calculation, which means that the possibility of type 2 errors is uncertain (26). Over a 33-month period, study invites were distributed to every patient added to the heart transplant waiting list at 'Vanderbilt University Transplant Centre' (in America) who met the study's clearly stated inclusion/exclusion criteria. The recruitment dates were not reported although this has implications for generalising the results given the advancements that have been seen in heart transplant procedures over recent years (27). In total 31 of the 41 eligible patients (76%) opted-in and completed the study. This is a reasonably strong recruitment/retention rate although the possibility of a response bias cannot be dismissed, as there was insufficient exploration of the differences between the final sample and those who failed to opt-in or were lost to follow-up (28). All potential participants had to be physically well enough to complete the study's questionnaires, and those who had received previous transplants were excluded. Consequently, this sample is biased towards healthier transplant candidates with better post-transplant prognoses (29). In addition the final sample only included 2 women and 2 non-Caucasian participants, which limits the generalisability of the results. Furthermore the age-range of participants was relatively broad (20 - 62 years old), as was the length of time they had spent on the transplant waiting list (1 month - >13months). These variables are possible confounding factors that could have influenced the key variables measured, and should have been controlled within the study's analysis.

This was a cohort study that employed a prospective longitudinal design. Data collection questionnaires were initially distributed when participants were added to the transplant waiting list. These were then redistributed: (i) when the participants were discharged after their transplant; (ii) at 3 months post-transplant; and (iii) at 6 months post-transplant. At all time points, information was also gathered from a single transplant nurse who knew the participants well. The repeated measurement of variables across time makes this an optimal design for drawing inferences about how patients' pre-transplant expectations affect their later outcomes, and it also removes the possibility of a recall bias affecting participants' reports of their pre-transplant expectations (30). As with all self-report measures, it is possible that those used in this study were subject to social desirability responding and that they could have introduced a selection bias in only being accessible to potential participants who had adequate literacy skills to complete them independently (31; 32). Nonetheless, self-report measures have the strength of recognising patients as experts in judging their own experiences of issues such as emotional wellbeing (33). In addition, this study also took steps to protect participants' identities when returning their data collection questionnaires (32).

Another key strength was that this study adopted a relatively broad operational definition of "post-transplant outcomes"; investigating both participants' psychological adjustment and physical health following heart transplantation. Two valid and reliable standardised questionnaires were used in the assessment of participants' psychological adjustment: The Profile of Mood States (POMS) and The Global Adjustment to Illness Scale (GAIS) (35; 36). All other post-transplant outcome measures used in the study were developed by the research team and previously untested in terms of their validity and reliability, which is a weakness (28).

Positive expectations were assessed through a self-report questionnaire that had been developed specifically for this study. The scale measured participants' beliefs about the likely efficacy of their transplant and their chance of obtaining future health/survival, as well as their general feelings about the future. This was not a standardised tool although one positive aspect of the study was that the researchers calculated the scale's internal consistency and found this to be high (30; 37). Furthermore it could also be argued that the use of multiple questions within this scale is a strength, relative to how other studies operationalised "pre-transplant expectations", as it recognises these were unlikely to be unitary in focus. Higher scores on this tool indicated possession of more positive expectations. The subscale midpoint score was 28 points and it would be achieved if participants had given neutral answers across all constituent items. It was reported that only 1 participant scored slightly below the subscale midpoint before transplantation, which suggests a possible ceiling effect.

To examine post-transplant adjustment in the face of negative health events, the study's sample was split at the median pre-transplant expectation score obtained. This produced a 'high pre-transplant expectation group' and a 'low pre-transplant expectation group'. There were twelve participants in each of these groups who had suffered at least one complication within their first 6 months of post-transplant life. No significant differences were detected between these groups' scores on any of the 6 months post-transplant adjustment measures ($t_s = .18 - .87$, $p_s > .40$). From which it was inferred that if one is going to face discouraging feedback, initial high hopes are *not* detrimental. Nonetheless the validity of this conclusion is uncertain given that splitting the sample at its median would have resulted in two groups in which almost all participants scored above the midpoint of the pre-transplant expectation scale and therefore held neutral-positive expectations.

Further analysis revealed a tendency towards a positive correlation between participants' pre-transplant expectations and the time until they experienced their first post-transplant infection, although this relationship did not reach significance ($r = .28$, $p < .15$). The research team also performed a partial multiple regression analysis using the nurse's ratings of post-transplant health as the dependent variable. The results revealed that participants' pre-transplant expectations were a strong predictor of post-transplant health, explaining over 40% of the unique variance in post-transplant health as rated by the participants' transplant nurse, after covarying for adherence to medical advice and pre-transplant health (change in $R^2 = .35$, adjusted $R^2 = .46$), $F(3, 27) = 7.73$, $p < .01$. One arguable weakness of this study's analysis was that participants were excluded from calculations when there was missing data on them (e.g. an incomplete questionnaire) (38; 39).

Lee et al. (2003, 16) investigated whether optimistic pre-transplant expectations were associated with higher survival rates following hematopoietic stem cell transplantation, after controlling for known predictors of survival. One strength of this study was its employment of consecutive sampling, which promotes its external validity, although a power calculation was not used to inform the sample size (25; 26). Potential participants were recruited from the stem cell transplant waiting lists of two medical establishments in America. A total of 458 potential participants were identified who met the study's inclusion/exclusion criteria. All 458 were invited to participate between August 1996 and November 1999. In total 313 opted-in and completed the study (68%). Unfortunately there was no clarity around how many potential participants had failed to opt-in and how many were lost to follow-up (or the reasons behind this). Nonetheless, one strength was that possible demographic differences were explored between the final sample and potential participants who did not complete the study (28). Participants in the final sample were more likely to be older and Caucasian; however there were

no differences in terms of sex, disease stage, and the specific type of stem cell transplant procedure that was received.

This study employed a prospective longitudinal design, which allows casual inferences to be drawn about how variables interact over time and prevents recall biases affecting the results (30). Notably, stem cell transplant procedures are now more advanced than when this cohort were recruited which could reduce the generalisability of the results (40). Questionnaire data were collected from participants before transplantation and at 6 months post-transplant. Again the self-report measures used in this study could have introduced a social desirability responding bias and would only be accessible to potential participants who had adequate literacy skills to complete them (31; 32). Furthermore, no measures were reported to protect participants' anonymity when returning their data collection questionnaires which is a weakness (34).

This study was strengthened by its adoption of a relatively broad operational definition of "post-transplant outcomes". This study investigated the effect of pre-transplant expectations on three important outcomes: survival; quality of life; and the experience of "bothersome symptoms". Post-transplant survival was ascertained through a review of the participants' medical records, whilst quality of life was assessed via two valid and reliable standardised questionnaires: 'The Medical Outcomes Study Short Form 36' (SF36) and 'The Spitzer Quality of Life Index' (QLI) (41; 42). Participants' experience of "bothersome symptoms" was evaluated through a series of Likert-scales developed by the research team. The "bothersome symptom" questions were not detailed within the study's report, however the validity and reliability of the "bothersome symptom" scales had never been tested prior to this study, which suggests caution is necessary when interpreting results based on these measures (28).

Pre-transplant expectations were classified according to participants' level of agreement with two statements "I am optimistic that my transplant will go well" and "If anything can go wrong with my transplant, it will". Participants who endorsed strong agreement with the first statement and strong disagreement with the second statement were considered to have "high expectations" compared to all the other response combinations. This is an unstandardised measure and its face validity seems uncertain given that participants would be categorised as having "low expectations" even if they were actually reporting agreement with the first statement and disagreement with the second (37). It also vaguely operationalises pre-transplant expectations and could result in participants using different interpretations of the phrases "go well"/"go wrong" (e.g. as referring to their physical health, or their psychosocial wellbeing).

Univariate comparisons were used to explore whether there were any differences between participants who had experienced “high” versus “low” pre-transplant expectations in terms of their quality of life or experience of “bothersome symptoms” at 6 months post-transplant. It was reported that there were no significant differences between these two groups on the SF36, the QLI, or any of the “bothersome symptom” items. One weakness was that no information was provided about the kind of “univariate comparisons” that were conducted (25). The participants’ survival data were also analysed through multivariate models, built using a forward stepwise approach. This is strong analysis that results in the smallest possible set of predictors included in the final model (39). The results showed that participants with low pre-transplant expectations had a significantly higher risk of mortality across their first two months of post-transplant life, compared to participants who had held high pre-transplant expectations, after controlling for disease stage, patient age, and the presence of acute graft-versus-host disease (16% vs 8%; RR 2.20, 95% confidence interval [CI] 1.08-4.46; $P=.03$). Nevertheless, the results showed that participants with high and low pre-transplant expectations had an equal risk of mortality after their first two months of post-transplant life. In addition it was also noteworthy that missing data were managed by removing potential participants from the final sample, and data analysis, which is a technique that has previously been argued as not being the most optimal approach for dealing with missing data (38; 39).

Andrykowski et al. (1995, 11) investigated how discordance between patients’ pre-transplant expectations and their “return to normal” post-transplant, interacted with their psychological distress levels following bone marrow transplantation. Potential participants, who met the study’s inclusion/exclusion criteria, were identified from the medical records of five bone marrow transplant centres in America. In total of 284 potential participants were invited to take part, and 173 opted-in. The use of consecutive sampling was a strength, although a power calculation was not used to inform the sample size (25; 26). To be eligible for recruitment potential participants had to be in disease remission, which could mean that the final sample was biased towards patients who were likely to have more optimal transplant experiences. Furthermore the generalisability of the study’s results could also be threatened by the narrow demographic profile of the final sample: 62% were male; 66% were married; and 62% were graduates of tertiary educational establishments (30). In addition ‘time since transplant’ ranged from 12 - 124 months, with the earliest transplant having taken place in 1980 and the latest in 1990. The challenges faced one year post-transplant are likely to be significantly different from those experienced ten years later, and across the 1980’s there were significant advances in bone marrow transplantation (43). Time since transplant could therefore be an important confounding factor that should have been controlled in the study’s analysis (25). The broad age range

of the recruited sample (19-70 years) also poses similar difficulties. The final sample's demographic and clinical characteristics were presented in detail, but were not compared with those of potential participants who did not opt-in (28). The study's results could therefore be subject to a response bias and not representative of the wider population, in that the experiences of the non-responders could be significantly different from those in the recruited sample (44).

This study employed a cross-sectional design. When participants opted-in they were interviewed over the telephone and sent questionnaires to complete. This approach is weakened by its reliance upon participants' recall of their pre-transplant expectations, which could become more vague with the passage of time (15). In addition, if participants suffered difficulties following their transplant this could have made them reluctant to admit they once held high pre-transplant expectations (e.g. due to embarrassment) (15). It is also not possible to infer cause and effect relationships through this type of design (45). Moreover, despite the benefits of telephone interviewing (e.g. it offers participants' visual anonymity which could decrease social desirability responding), the technique also has a number of drawbacks that may have negatively impacted the validity of the study's results (e.g. miscommunications are more likely using this data collection method than through alternative approaches) (46). The self-report questionnaires used in this study would also require a certain level of literacy skills in potential participants, and could have been weakened by social desirability responding (31; 32). No steps were reported to protect participants' response anonymity when returning their data collection questionnaires (34).

Two post-transplant outcomes were measured in this study. The first was post-transplant psychological distress, which was measured through four valid and reliable standardised questionnaires: The Profile of Mood States (POMS); The Psychological Adjustment to Illness Scale (PAIS); The Rosenberg Self-Esteem Scale (RSE); and The Positive and Negative Affect Scale (PANAS) (35; 47; 48; 49). The second post-transplant variable explored was "normalcy". This was determined through a single open-ended interview question "Do you consider yourself to have returned to normal following your transplant?". This is an unstandardised measure, and the uncertainty around its validity and reliability is a weakness (28). For example, participants could vary greatly in their subjective definitions of what "normal" means, making it unclear what is actually being measured. Nonetheless, one strength of this study was that three researchers independently coded all of the participants' responses with a high level of inter-rater agreement (85%).

In this study, pre-transplant expectations were operationalised through a single open-ended interview question “Prior to your transplant, did you expect that you would have returned to normal by this time?”. This is an unvalidated measure that poorly defines ‘pre-transplant expectations’ and has unknown reliability, which is a weakness (30; 37).

Andrykowski et al (1995) explored the relationship between expectation-outcome discordancy and current psychological distress through a two-way ANOVA. Psychological distress was used as the dependent variable, whilst the two independent variables were pre-transplant expectations and normalcy. A significant interaction effect was found ($F(1,90) = 4.07; P < 0.05$). This suggested that participants’ current psychological distress was unrelated to whether they viewed themselves as having “returned to normal” when they had not expected this to happen pre-transplant. Nonetheless higher levels of psychological distress were found in patients who perceived themselves as not having returned to normal, when they had expected this to happen pre-transplant. One important weakness was that the effect size of this interaction was not reported (26). In addition, 73 participants (42% of the recruited sample) were excluded from the ANOVA because their responses on the pre-transplant expectation measure could not be neatly categorised into “yes” or “no” answers.

Holzner et al. (2001, 15) examined how patients’ pre-transplant expectations were related to their self-perceived quality of life and normalcy following liver transplantation. All patients who had received a liver transplant at ‘Innsbruck University Hospital’ (in Austria) between 1987 and 1997 were invited to participate who met the study’s inclusion/exclusion criteria. This study’s consecutive sampling approach to recruitment strengthens its external validity, although a power calculation was not employed to inform the sample size (25; 26). To be eligible for recruitment potential participants had to have no severe illnesses other than kidney failure, which could bias the final sample towards healthier patients (32). In total 62 potential participants were identified, but 7 were excluded after returning incomplete questionnaires. It was reported that these 7 patients did not differ markedly from the final sample in terms of their clinical characteristics, although no data was provided to confirm this.

A cross-sectional design was employed which is a weakness given that the accuracy of the collected data was reliant upon participants’ recall of their pre-transplant expectations (15). In addition, it is also not possible to infer cause and effect relationships through this type of design (45). Furthermore, time since transplant differed markedly between the participants, which is a potential confounding factor. Participation comprised of a telephone interview and the self-completion of study questionnaires. Telephone interviews have strengths although the potential for miscommunications is

heightened relative to face-to-face interviews (46). One strength of this study was that the same interviewer conducted all of the interviews; which should ensure a degree of consistency in how the interviews were conducted. As previously discussed, self-report measures require potential participants to have the literacy skills needed to complete them, and can be weakened by social desirability responding (31; 32). No measures were reported to protect participants' response anonymity when returning their data collection questionnaires (34).

The post-transplant measures assessed in this study were self-perceived normalcy and quality of life. "Normalcy" was assessed through a single interview question "Would you say that through transplantation your life has normalised again?". Response categories were: "yes"; "with some limitations"; and "no". This is an unstandardised measure that vaguely operationalises normalcy which is a weakness (28). For example, the participants could have interpreted the question in different ways (e.g. some might have thought that changes in their physical health was being queried, whilst others might have believed changes in their mental health or ability to engage in social activities was being questioned). Quality of life was assessed through two valid and reliable standardised questionnaires which is a strength, the German version of 'The Sickness Impact Profile' and 'The Functional Assessment of Cancer Therapy – General (FACT-G)' (50; 51).

In this study pre-transplant expectations were assessed through a single interview question, "Before transplantation, did you expect your life would normalise after the surgery?". This is an unstandardised measure, which is a weakness (30; 37). Furthermore, it only offers a vague operational definition of pre-transplant expectations. It was reported that the possible response categories were: "positive expectations"; "negative expectations"; and "no expectations at all". Although no further details were provided about how the process of coding participants' answers was approached.

The collected data were analysed using two-way ANOVAs. The results showed that when FACT-G scores were used as the dependent variable, there was a significant interaction between participants' pre-transplant expectations and their return to normal post-transplant ($F_{1,46} = 5.11, p = 0.029$). Further analysis revealed that when participants *did not* view themselves as having returned to normal post-transplant, those who had expected to obtain normalcy described themselves as having a significantly lower quality of life than those who had never held such expectations (Mann-Whitney *U* test, $p < 0.023$). No relationship was found between pre-transplant expectations and post-transplant FACT-G scores in the group of participants who *did* view themselves as being back to normal post-transplant. The effect size of these results was not reported which is a weakness (26). Interestingly when SIP scores were

used as the dependent variable (instead of FACT-G scores) no interaction effect was evident between the participants' pre-transplant expectations and their return to normal post-transplant. This is unexpected given that both are designed to measure the same construct, quality of life. One potential weakness of this study was that a small number of participants were excluded from the analysis because their pre-transplant expectations could not be discretely categorised as either positive or negative. Furthermore the independent variable "post-transplant normalcy" had only two levels and to create this two-way split the answers "no (I have not returned to normal)" and "yes, with some limitations" were merged together into one level.

Pommer et al. (1985, 23) investigated the relationship between patients' pre-transplant expectations and the health of their donor organ 3 months after kidney transplantation. The recruited sample comprised of 83 patients who had been admitted to "the transplantation programme" since 1982. No details were provided about "the transplant programme", about any inclusion/exclusion criterion employed during recruitment, or about the final sample's demographic/clinical profile. These are weaknesses that make it difficult to judge the representativeness of the final sample (28). Nonetheless, the prospective longitudinal design of this cohort study was a strength (30). It was reported that questionnaires were used to gather information about participants' pre-transplant expectations before they underwent the procedure and that the health of their donor organ was ascertained through medical records 3 months post-transplant. Unfortunately the quality of this study's procedure cannot be determined as it was insufficiently detailed in the final report. For example there was no clarity as to whether questionnaires were administered in a transplant centre by a clinician whom participants knew well, even although the lack of anonymity inherent within such a situation could impact on how comfortable participants would feel in sharing information openly and honestly (34).

The only outcome measure in this study was whether participants' donor kidneys were still healthy at 3 months post-transplant (dichotomised as "successful" or "unsuccessful" transplants). Unfortunately the operational definition of "successful" was not explicitly stated (e.g. it might mean loss of functioning below a certain level or complete rejection of the transplanted kidney). In addition, this measure is also narrow in its focus. For example, patients' pre-transplant expectations could impact on other important domains of functioning outwith the physical health sphere (e.g. patients' emotional wellbeing), yet this is not considered (15).

In this study, pre-transplant expectations were measured through an 8-item self-report questionnaire developed by the research team. Some of the questionnaire items appeared to have face validity but were vaguely operationalised, for example, “self-estimation of *general condition* 3 months after transplantation”. Nonetheless, other items on the questionnaire did not seem likely to tap ‘patient expectations’ at all, for example “self-estimation of recommendation of kidney transplantation to a close friend”. In addition, the reliability and sensitivity of this questionnaire was completely untested, which is a weakness (30; 37).

This study only used descriptive statistics in its data analysis. In total, 40% of participants’ were categorised as having unsuccessful transplants 3 months after the procedure. It was reported that this subsample had “distinctly lower scores of predicted transplant success” than the 60% of participants whose transplants *were* successful after 3 months. This study may be criticised on the grounds that the phrase “distinctly lower scores” is very vague and the expectation scores of these two groups’ were not actually reported in the paper (26). Furthermore without the use of an inferential statistical analysis, the significance of any apparent between group differences cannot be determined (26).

Data Synthesis

This systematic review aimed to answer the question “do patients’ pre-transplant expectations impact their post-transplant outcomes (physical health status and psychosocial adjustment)?”. Five research papers were identified that explored this relationship. Due to these studies’ considerable heterogeneity (e.g. in terms of their sample characteristics and designs), their findings could not be collated and appraised via meta-analysis (52). In total, three studies explored whether patients’ pre-transplant expectations influenced their post-transplant physical health outcomes (1; 16; 23). One of these studies was of “good quality” and found that positive pre-transplant expectations were a strong predictor of nurse-reported patient health following heart transplantation (after controlling for patients’ adherence to medical advice and their pre-transplant health), but had no impact on patients’ vulnerability to infections/rejections post-transplant as recorded in their medical case-notes (1). The second study was also of “good quality” (16). It found that patients who experienced low pre-transplant expectations had a significantly higher risk of mortality across their first two months of life following stem-cell transplantation; compared to patients who had held positive pre-transplant expectations (after controlling for disease stage, patient age, and the presence of acute graft-versus-host disease). Nevertheless, this vulnerability seemed time-limited as both groups were found to have an equal risk of mortality after their first two months of post-transplant life, and when compared at 6 months post-transplant there was no difference in their self-reported experience of “bothersome

symptoms". In contrast to the first two studies, the final study that investigated the relationship between patients' pre-transplant expectations and their physical health post-transplant was of "poor quality" (23). This study offered results suggesting that low pre-transplant expectations might heighten the risk of having an "unsuccessful" kidney transplant, although it did not use inferential statistics to investigate whether this relationship was statistically significant.

In total, four studies explored whether patients' pre-transplant expectations influenced their post-transplant psychosocial adjustment (1; 11; 15; 16). The two "moderate quality" studies included in the review reported results suggesting that when patients experience unfulfilled pre-transplant expectations that they would "return to normal" post-transplant (11; 15), they are more likely to report higher levels of psychological distress following bone marrow transplant and a lower quality of life following liver transplant (although the latter relationship did not hold across different quality-of-life rating tools). In contrast to these results, the two "good quality" papers found no significant relationships between patients' pre-transplant expectations and their psychological wellbeing / quality of life following heart transplantation and stem cell transplantation (1; 16). Although in these studies comparisons were drawn between patients with "high" versus "low" pre-transplant expectations; rather than those with "fulfilled" and "unfulfilled" expectations.

DISCUSSION

Summary of Evidence

This systematic review identified five research papers that explored the relationship between patients' pre-transplant expectations and their post-transplant outcomes.

In total, three of the studies offered evidence consistent with the hypothesis that patients' pre-transplant expectations might influence their post-transplant physical health status. In summary, one "good quality" study found that positive pre-transplant expectations were a strong predictor of nurse-reported patient health following heart transplantation (1); one "good quality" study found that low pre-transplant expectations heightened patients' risk of mortality across the first two months of life following stem-cell transplantation (16); and one "poor quality" study found that low pre-transplant expectations heightened patients' risk of having an "unsuccessful" kidney transplantation (23). Nonetheless, in contrast to these findings, the two "good quality" studies also found that patients' pre-transplant expectations had no impact on their: vulnerability to infections/rejections following heart transplantation (1); risk of mortality 3 - 6 months after stem-cell transplantation (16); or experience of "bothersome symptoms" 6 months following stem-cell transplantation (16).

In total, two of the studies included in the review provided evidence consistent with the hypothesis that patients' pre-transplant expectations might influence their post-transplant psychosocial adjustment (11; 15). These two studies were of "moderate quality". Their results suggested that when patients experienced unfilled pre-transplant expectations that they would "return to normal" post-transplant (11; 15), they were more likely to report higher levels of psychological distress following bone marrow transplantation, and a lower quality of life following liver transplantation. Nonetheless, in contrast to these results, the two "good quality" studies included in the review, found no significant relationships between patients' pre-transplant expectations and their psychological wellbeing/quality of life following heart transplantation (1) and stem cell transplantation (16).

Unfortunately these conflicting results make it hard to draw conclusions about whether patients' pre-transplant expectations impact their post-transplant outcomes (physical health status and psychosocial adjustment). It seems possible that these contradictory findings could be explained by differences in the quality of these five studies, or by the complexity of comparing investigations that have employed different methodological approaches (53).

Methodological Limitations of The Reviewed Studies

None of the included studies employed a power calculation to determine their sample size. This omission potentially weakens each study, particularly those with relatively small samples, as it increases the risk of type 2 errors (26). Furthermore the exclusion criteria used in three studies reduced the likelihood of less healthy patient subgroups being recruited, which reduces their external validity (29; 32). Within and between studies there was also considerable variability in the recruited participants' demographic profiles including their pre-transplant medical histories, age, and ethnicities. Such factors can operate to confound a study's results, and should have been controlled within the studies' analyses (25). In addition, variability in participant demographics also limits the possibility of making confident cross-study comparisons. (32). It is also important for researchers to explore whether identifiable differences exist between their final sample and any potential participants who were invited to take part but failed to opt-in (28). This is because non-response might reflect a confounding factor that could operate to bias the obtained results (28). Only one study offered a detailed comparison of these two groups in their report and backed up their conclusions with inferential statistics (16).

The risk of sampling strategies biasing a study's findings also depends on the approach taken to data collection (37). Limited information was offered in any of the included studies' about how their participants were approached during recruitment. This represents a significant weakness. Moreover, all five studies used self-report questionnaires to gather research data but these tools are reliant upon participants' literacy skills; a potential barrier to participation (31; 32). Furthermore, self-report measures can also be subject to social desirability biases and in most of studies it was unclear if participants' would feel their response anonymity was protected (31). For example, only one study reported using a strategy to anonymise participants' identity when they submitted their data collection questionnaires (1). Two of the included studies also utilised telephone interviews to gather data. This strategy offers participants visual anonymity, but misunderstandings are more likely than when using face-to-face interviewing as all nonverbal communication is lost (46). In addition, it was also unclear in one of these studies whether the telephone interviewer was a clinician routinely involved in delivering the participants' healthcare, even although this could have heightened the risk of social desirability responding (e.g. if participants' feared their future healthcare would be compromised by the voicing of negative experiences) (11).

Three studies utilised prospective longitudinal designs (1; 16). This was arguably the strongest research design as it permitted participants to be followed-up over time; which allows casual inferences to be drawn about how patient expectations measured before transplantation relate to patient outcomes measured post-transplant (8). Nonetheless one important drawback of using longitudinal designs, which impacted two of these longitudinal studies, is the risk of losing participants to follow-up (1; 16). In these two studies this particular difficulty was managed by removing participants with missing data from their final analyses, which could threaten their internal validity (38; 39). The other two studies included in the review employed cross-sectional designs (11; 15). As a result, they were weakened by their inability to track changes in patient outcomes at different stages of their post-transplant life, and by their reliance upon participants' recall of their pre-transplant expectations (15).

All of the studies differed in their outcome measures and at what stage of post-transplant life they administered these to participants. This is a significant shortcoming that makes it hard to synthesise the studies' results (37). Moreover, many of the studies also constructed their own unstandardised post-transplant outcome measures, which could compromise their internal validity (28). In addition, one of the reviewed studies only assessed participants' physical health status post-transplant (23); whilst another two studies only assessed participants' psychosocial functioning post-transplant (11; 15). This restricted operationalization of post-transplant outcomes is a weakness. The strongest approach possible was to take measurements of both participants' physical health status and their psychosocial functioning post-transplant, as was done in the two "good quality" studies (1; 16).

All of the studies included in the review differed in how they defined and operationalised pre-transplant expectations, and each made up their own unstandardised tool to assess this variable. Most opted for vague measurements such as asking participants whether they had anticipated a return to normal post-transplant. This makes it hard to compare the studies' results and endangers their validity (37). In addition, it is also possible that all of the studies may have over-simplified complex constructs such as 'pre-transplant expectations' in trying to investigate them quantitatively through data collection tools that restricted participants' self-reports to a pre-set range of response options (32).

In terms of analysis, one study only reported descriptive data and so there was no way to know whether the relationship it reported was of statistical significance (23). All of the other studies utilised inferential statistical techniques but they did not consistently report the effect sizes of their results, which means their clinical significance is uncertain (26).

Limitations of The Review

The search strategy used to identify articles in this review was limited because “post-transplant outcomes” were not included in the range of employed search terms; the adoption of a PICOS approach (participants, interventions, comparators, outcomes, and study design) would have resulted in a more robust search strategy (54). Another of this review’s main weaknesses was that cross-study comparisons were impeded by the heterogeneity of participants’ underlying illnesses and the significantly different types of transplants that they had therefore received. In addition, the existing grey literature was not explored which means that the results could be subject to a publication bias (55). All included articles were written in English, which also introduces the risk of a language bias (37). Furthermore, the included studies were conducted in different countries and cultural biases could have affected how the participants experienced and reflected upon their transplant operations (25). This review excluded qualitative studies and some authors have proposed that lived experiences such as undergoing transplantation surgery are too complex to be accurately captured using quantitative methods (32). It would therefore be valuable to conduct a review of qualitative studies that have explored the relationship between pre-transplant expectations and post-transplant outcomes in the future. The quality of the five studies included in this review were also critiqued separately in turn within the results section of this report. The review would have been strengthened if the PRISMA Statement checklist had been followed on how to coherently synthesise data across studies in a systematic review report (54).

Clinical Implications, Future Research and Conclusion

Although some of the papers included in the review have offered evidence of a relationship between patients' pre-transplant expectations and their post-transplant outcomes, this finding has not been consistently replicated across studies and in general the previous quantitative research exploring this relationship is not robust. As a result, it is not possible to make clinical recommendations based on the review's findings. Additional research is warranted, with a higher degree of methodological rigor to allow a more definitive conclusion to be reached that could be used to inform clinical practice. Nonetheless, this review offers a platform from which new studies can be developed that address the limitations inherent within the existing literature. When conducting future quantitative studies in this area they should ideally employ a prospective longitudinal design and statistically powered sample size. Moreover it would also be beneficial to explore the relationship between patients' pre-transplant expectations and post-transplant outcomes more thoroughly within specific types of transplant patient groups (who have the same underlying illness). To aid cross-study comparisons, it would also be important for future studies to operationalize "pre-transplant expectations" and "post-transplant outcomes" more clearly and to measure them using the same instruments; the development of new standardised tools could help this process. In addition, if a robust relationship were to be established between patients' pre-transplant expectations and their post-transplant outcomes, it would be valuable for future research to investigate how patients develop their pre-transplant expectations. For example, whether patients' pre-transplant expectations reflect their personality (e.g. having an optimistic disposition) or other factors such as their attachment style. This could aid the development of new intervention approaches to help patients achieve the best post-transplant outcomes possible.

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CHAPTER 2: Major Research Project

Young People's Experiences and Expectations of Successful Renal Transplants

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(D.Clin.Psy)

LAY SUMMARY

The reason for this study: Kidney failure is a life-threatening health condition that can occur at any age. One of the best treatments available is receiving a new kidney to replace the damaged one - a kidney transplant. Kidney transplants do not last forever and each will eventually have to be replaced. The design of the human body means that transplanted kidneys will be rejected and lost unless people follow strict self-care behaviours after having their transplant operation (e.g. take medication and meet fluid intake requirements).

Young people who are aged between 11-17 years old, have a higher risk of losing their transplanted kidney than younger or older patients. This vulnerability is thought to be partly due to young people being less likely to take their medications after having their transplant operations. Young people are also vulnerable to developing mental health and social difficulties following their kidney transplants. The 'prefrontal areas' of the brain are not fully developed during adolescence. These are the parts of the brain that are needed for risk assessment, problem solving, making 'good judgments', and predicting the future consequences of current actions. Until these brain areas are fully developed young people are more at risk, than adults, of overlooking the long-term dangers of not looking after their kidney transplant. Due to their developmental stage, young people are also more likely than adults to believe that bad things only happen to others. This increases the chance that they might expect only positive outcomes after having a kidney transplant which would leave them unprepared for the possibility of negative outcomes. Unfulfilled pre-transplant expectations could be experienced as a loss and leave young people vulnerable to mental health difficulties like depression or anxiety. It is therefore important to learn more about young people's personal experiences of having a kidney transplant.

Aims: To learn more about young people's experiences of having a kidney transplant.

Method: Four young people (aged 14-17 years old) were interviewed about their experience of living through a successful kidney transplant operation.

Results: Three main themes emerged from the participants' interviews: pre-transplant struggles; coping; and post-transplant adjustment. It appears that young people living through kidney transplant operations want to lead 'normal' lives similar to their healthy peers but face several barriers to achieving this, which they cope with using a range of different strategies. Furthermore, the results also suggest that the expectations some young people hold before having their kidney transplant can

impact their emotional wellbeing, and ability to adjust to their new self-care behaviours, post-transplant.

This study helps to build our understanding of how young people experience the kidney transplant process; and provides many unique insights into how they experience this treatment. Although this study has limitations, its results have important clinical implications and indicate many new ideas for future research.

ABSTRACT

Background: Kidney transplantation is currently the treatment of choice for young people with life-threatening kidney failure. After receiving a kidney transplant young people must adhere to a strict medication regimen to prevent their body from rejecting their transplanted kidney. Those who are between 11-17 years of age have been identified as being at increased risk of losing their transplanted kidney and this vulnerability has been partly attributed to medication non-adherence. Adolescence is a period of transition when several important developmental tasks must be undertaken such as building self-identity and achieving independence. Adolescence could impact the success of kidney transplantation in multiple ways. Given that young people are likely to think differently from other age groups due to their developmental stage (neurological, cognitive, and social), it is important to learn more about their self-reported lived experience of having a kidney transplant. Before receiving a kidney transplant, young people are likely to have experienced a period of significant ill-health and to have considered how this might improve post-transplant. It is possible they may use their pre-transplant expectations as a baseline for gauging later transplant success. Although it is recommended that expectations be one of the key elements considered during young people's pre-transplant psychosocial assessments there is limited research focused upon this critical area.

Aims: To build a detailed understanding of young people's lived experience across the kidney transplant process, from the point of forming their pre-transplant expectations, and to learn more about the meaning they construct around this experience.

Methods: Four young people (aged 14-17) who had received a successful kidney transplant within the past five years completed a non-directive semi-structured interview about this experience. Interview transcripts were analysed using Interpretative Phenomenological Analysis.

Results: Three superordinate themes emerged from the data; 'Pre-transplant struggles', 'Coping', and 'Post-transplant adjustment'. It was clear that at all stages of the transplant process, young people wanted to lead 'normal' lives similar to their healthy peers. Nonetheless they faced several difficult challenges to obtaining this, which they coped with using a range of different strategies. All of the participants' pre-transplant expectations were linked to the general belief that life would become "normal" post-transplant. Most participants reported complete fulfilment of their expectations, yet contradicted this in describing a conflicted sense of being both "the same as" and "different from" their peers post-transplant. Interestingly, one participant reported their pre-transplant expectations

had been markedly inaccurate. They said this had not only caused them considerable distress post-transplant, but also impeded their ability to accept their donor kidney and new self-care behaviours.

Conclusions: Young people's lived experience across kidney transplantation appears to be characterised by pre-transplant struggles, making post-transplant adjustments, and finding ways to cope with difficult circumstances. Many of the study's findings parallel the results of previous research but there have also been several novel insights into this experience, such as the significance of organ integration processes during young people's post-transplant adjustment. This study also offers preliminary support to the proposition that young people's pre-transplant expectations can play an instrumental role in determining their psychological wellbeing, and their adaptation to new self-care behaviours, post-transplant. Several new directions for future research are indicated.

Key words: Kidney transplant; renal transplant; expectations, lived experience; adolescence

INTRODUCTION

End stage renal disease (ESRD) is a life-threatening medical condition that represents the last phase of chronic kidney failure (1). Kidney transplantation is currently the treatment of choice for patients who have ESRD (2; 3). Through the delivery of a functioning donor kidney the procedure aims to prolong life, improve physical health, and enhance quality of life (4). Following transplantation patients must take immunosuppressant medications and meet daily fluid consumption requirements to prevent the body from rejecting the transplanted kidney (1). Post-transplant, patients are at risk of developing secondary medical problems such as reduced bone mass, infection, anaemia, and loss of functioning in their transplanted kidney (5; 6; 7; 8). Kidney transplantation is not a curative treatment and patients usually require further interventions, such as an additional transplant, at a later date (7; 8).

Younger patients, aged 11-17 years old, have been identified as a population who are at high risk of losing donor kidneys following successful transplant operations (9). This vulnerability has been partly attributed to medication non-adherence (10). Research suggests this population is also vulnerable to a range of post-transplant psychosocial adjustment difficulties including anxiety, depression, low self-esteem, relationship problems, body image concerns, and poor academic achievement (7; 11; 12).

Adolescence is a period of transition when several important developmental tasks must be undertaken such as building self-identity and achieving independence (10). Adolescence could have a multi-faceted interaction with the success of kidney transplantation. Peer opinion is very important during adolescence (13). Those who have received a kidney transplant may be reluctant to take their medications to minimise feelings of difference from peers or if they view non-adherence as a way to distance themselves from an identity as a sick person (1). In addition, young kidney transplant patients are likely to require significant support from the adults in their lives and could feel indebted to any family member who had offered them a donated kidney (14; 15). This dependence and sense of being in debt to family members could limit opportunities to experiment and learn from normal adolescent peer experiences that would ordinarily lead to independence. It could also make it more difficult for young people to perceive themselves as individuals, separate from their family system.

Research suggests that the prefrontal areas of the brain are incompletely developed during adolescence (16). These areas are associated with higher order cognitive functions such as risk assessment, problem solving, and impulse control which are necessary for making 'good judgments' and foreseeing the future consequences of current behaviours (17). Until this stage of neurodevelopment is achieved in the mid-twenties, young people are more likely to believe that they are unique and invulnerable (17; 18; 19). Given this, some young people may tend to expect positive

outcomes following kidney transplantation, which could leave them unprepared for any negative outcomes. Limited ability to recognise the long-term negative consequences of current actions also increases the likelihood that adolescents will engage in risky behaviours such as medication non-adherence, which could endanger a transplanted kidney (12). In short, future adverse consequences may not seem salient to adolescents who think and act in a more immediate time frame (20). Given that young people are likely to think differently from other age groups due to their developmental stage (neurological, cognitive, and social), it is important to learn more about their self-reported lived experience of having a kidney transplant. Recent studies have found differences between the self-reported quality of life of young kidney transplant patients and the estimates given by their parents and physicians, which underlines the need to consult young people about their own experiences (12; 1). Previous studies exploring young people's experiences of kidney transplantation have often failed to gather young people's own views and have largely used quantitative methods that may not capture the complexities of living through this experience (21). There is therefore a need for more qualitative research to explore young patients' self-reported lived experiences of end stage renal disease and its treatment through kidney transplantation (21). This would facilitate the development of a shared understanding of this experience that could be discussed with other young people who are considering kidney transplantation to help them make informed decisions and prepare adequately for their transplant.

Before receiving a kidney transplant, young people are likely to have experienced a period of significant ill-health and to have considered how this might improve post-transplant (22). One possibility is that they may use their pre-transplant expectations as a baseline for gauging later transplant success. Some young people may hold optimistic expectations (23). Optimism has been identified as a factor that may operate to protect mental and physical wellbeing (24). It is argued that people who tend to approach their difficulties with optimistic expectations are more likely to employ goal-directed thinking when unwell and concentrate upon the steps necessary for recovery when experiencing ill-health (25). Studies exploring the experiences of young people who have different types of chronic illnesses have found that optimism is associated with better adherence to medical advice, the use of more adaptive coping strategies, and lower levels of anxiety (26; 27).

It is recommended that expectations are one of the key elements considered during young people's pre-transplant psychosocial assessments but there is limited research focused upon this important area (28). One study to date has explored this subject in paediatric patients who had received different types of transplants (29). This study found that although the majority of participants described their post-transplant lives as similar to that of healthy peers, some described unmet

expectations of support from others that led to feelings of exclusion and dissatisfaction with post-transplant life (29). It is possible that patient adjustment may be adversely impacted when there is a negative discrepancy between their preoperative expectations and postoperative results (30). This kind of experience is likely to create a state of cognitive dissonance and induce feelings of loss.

Despite the lack of paediatric research focused on this area, we can draw on studies that have explored the pre-transplant expectations of adult transplant patients. Findings suggest that although global quality of life is better following kidney transplantation, adult patients' pre-transplant expectations are significantly higher than their actual post-transplant outcomes (31). A recent study on adult liver transplant patients found that when patients' physical and psychosocial functioning was poor post-transplant, those who had previously held optimistic expectations viewed themselves as having a significantly lower quality of life than those who had originally reported a more sceptical outlook (32). This finding contrasts with the protective quality of optimism suggested in the paediatric studies discussed previously (26; 27). It would be interesting to know more about the role of young people's pre-kidney-transplant expectations on their post-kidney-transplant outcomes. This understanding could be used to identify those at risk of developing psychosocial difficulties at an early stage in the transplant process in order to provide them with information about what to expect and to make them more ready for treatment.

AIMS

To develop a comprehensive understanding of young people's lived experience across kidney transplantation.

METHODS

Ethics

Ethical approval was obtained from the NHS West of Scotland Research Ethics Service (REC ref: 13/WS/0077, Appendix 6) and the NHS Greater Glasgow and Clyde Research & Development Service (ref: GN12KH566, Appendix 7).

Design

This qualitative study employed Interpretative Phenomenological Analysis (IPA), which has its theoretical underpinnings in phenomenology, hermeneutics, and idiography (33). IPA aims to build a comprehensive understanding of the phenomenon of interest by examining participants' personal lived experience through key events, the sense they have made of their experiences, and the meanings they have attached to them (33). IPA acknowledges that the researcher's phenomenological analysis is invariably an interpretation of participants' accounts (34). IPA recognises the importance of understanding the differences between people's experiences of the same phenomenon, as well as the similarities, and is particularly suited to the exploration of experiences that have received minimal prior investigation due to its focus on generating rich, in-depth data about the phenomenon of interest (34; 35; 36). IPA employs a 'bottom-up' approach to data analysis rather than attempting to mould data into pre-existing theories (34). IPA was specifically designed for the analysis of major life experiences and has been extensively applied in health psychology research (34). For these reasons, IPA was selected as the preferred methodology for this study.

Participants

Four young people who had received a successful kidney transplant participated in the study. This is consistent with the recommended sample size of between four and ten participants for IPA studies conducted at the professional doctorate level (34). The study inclusion criteria were chosen to permit recruitment of a reasonably homogeneous purposive sample consistent with IPA principles (34):

Inclusion criteria:

- (a) Participants will have had a successful kidney transplant and be under the care of the Renal Team at Yorkhill Royal Hospital for Sick Children (Yorkhill RHSC).
- (b) Time since transplant will be at least six months to allow a period of post-transplant adjustment, consistent with Anthony et al. (2010, 7).
- (c) Time since transplant must be no more than five years as the study requires participants to recall life before their transplant, consistent with Holzner et al. (2001, 32).
- (d) Participants must have the ability to speak English at a level that will permit them to provide a detailed account of their experiences.
- (e) Participants will be young people aged 11-17 years old.

Participant information is summarised in Table 1. Gender appropriate pseudo names have been employed to protect participants' anonymity.

Table 1: Participant Information

| Participant pseudo name | Gender | Age at interview | Time since transplant | Receipt of dialysis before transplant | Donor status |
|-------------------------|--------|------------------|-----------------------|---------------------------------------|----------------|
| Allison | F | 17 | 5 years | Haemodialysis and peritoneal dialysis | Deceased donor |
| Ben | M | 17 | 1 year | Haemodialysis and peritoneal dialysis | Deceased donor |
| Max | M | 14 | 1 year | Did not receive dialysis | Deceased donor |
| Josh | M | 16 | 5 years | Haemodialysis | Deceased donor |

Procedure

The renal nurse specialists at Yorkhill RHSC conducted a computerised search of their team's database, which identified a total of eight potential participants who met the study's inclusion criterion. During routine follow-up appointments the renal nurse specialists approached all potential participants to explain that the study was taking place, to distribute information packs, and to collect completed opt-in forms (Appendices 8; 9). Those who opted-in were contacted by the principal researcher (EW) who answered any additional questions they had and arranged an interview date. Four of the potential participants opted-in to the study.

Data were gathered during semi-structured interviews conducted face-to-face with the principal researcher. Informed consent was obtained prior to each interview, and from the parents of participants who were 16 years old or younger (Appendix 10). All participants were interviewed individually, in a quiet clinical room within Yorkhill RHSC. An interview schedule was developed for the study (Appendix 11), although the interviews were carried out in a flexible manner and guided by the salient issues that arose in participants' responses. Participants were encouraged to talk as broadly as possible about their experiences of kidney transplantation. Throughout the interviews, an emphasis was placed on establishing rapport and trying to understand each participant's perspective. The researcher used reflective listening, empathy, and summarising to facilitate the interview process and to ensure shared understanding of key points raised. The length of interviews ranged from 57 to 100 minutes with a mean time of 81 minutes. All interviews were transcribed by the principal researcher.

Materials

The interview schedule was developed from the key themes that previous studies had identified as significant across transplantation procedures (7; 11; 12; 29). Piloting with colleagues was used to refine the key questions and check sense. Open-ended questions were employed, with further probes as required, to encourage participants to elaborate on key themes (Appendix 11).

Data Analysis

Data analysis followed IPA principles (34). The initial stage of the analysis entailed repeated re-reading of the first transcript to attain thorough familiarity with the data. Following this, detailed exploratory notes were recorded in the right margin of the transcript document. These notes included descriptive, linguistic, and conceptual comments. Next the exploratory notes were focused upon and developed into emergent themes that were recorded in the document's left margin. The emergent themes comprised concise statements that captured the essence of the exploratory notes. The next stage entailed searching for patterns and connections between the emergent themes to identify that case's superordinate themes. Consistent with IPA's idiographic commitment, each transcript was thoroughly analysed on an individual basis before moving on to analyse the next transcript from scratch. When all of the transcripts had been analysed, the connections and patterns across cases were identified in order to produce a master list of superordinate themes for the group.

Reflexivity and Reliability

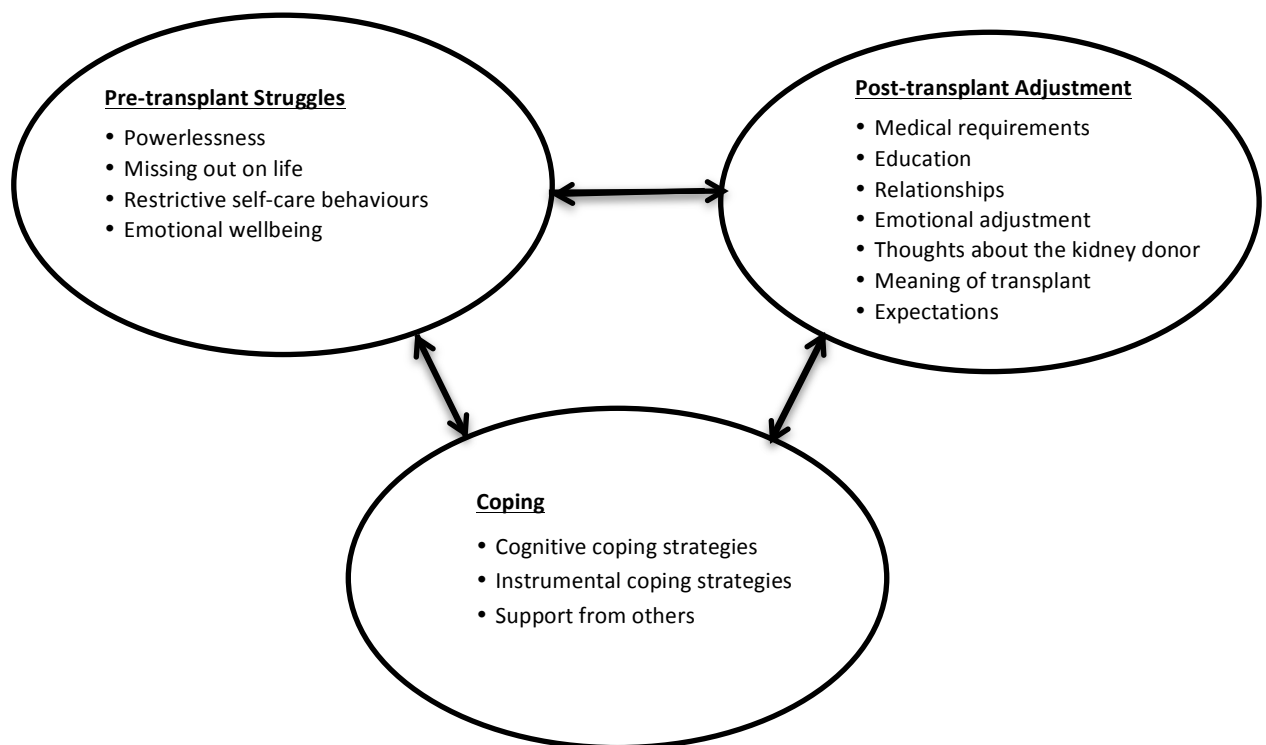
A reflexive approach is essential when using IPA (34). Researchers must be mindful of how their own experiences, beliefs and assumptions affect their interpretation of participants' accounts (34). For example, during the analysis stage the principal researcher noticed that media portrayals of young people with chronic illnesses often emphasise their vulnerabilities. Reflecting on this made the principal researcher aware that exposure to such depictions could have caused them to develop biased expectations about how chronically ill young people are likely to experience life. Although the principal researcher had no previous experience of working with adolescent kidney transplant patients, they did have experience of working with adolescents who had other chronic illnesses and had completed training placements in paediatric psychology services. These experiences offered them greater insight into the lives of adolescents who have chronic illnesses and the challenges they face.

Several measures were taken to ensure the analysis was carried out rigorously and the principal researcher's interpretations were explicit. A reflective journal was kept throughout the data collection and analysis stages to document the key decisions made in the process of identifying themes across the interviews. To examine the reliability and validity of the coding procedure, the first two transcripts were also independently analysed by the principal researcher's supervisors. Discussion of emergent themes ascertained that there was a high level of agreement in all initial coding choices.

RESULTS

Three superordinate themes were identified from the participants' interviews: (a) pre-transplant struggles; (b) coping; (c) post-transplant adjustment. These are discussed within this section and exemplified with verbatim extracts from the participants' interviews¹.

Figure 1: Superordinate themes



¹The following key is provided to aid understanding of the illustrative quotes:

- ... Short pause
- (...) Words omitted to shorten quote
- [text] Explanatory information included by the author
- X Initial of participant providing the quote

Pre-transplant Struggles (Theme A)

Powerlessness

A sense of being powerless repeated across all participants' accounts of their pre-transplant lives. Each had received a range of medical interventions up to and including their transplant operation. Most described objectification during these procedures as captured in Allison's recollection of being admitted to hospital for dialysis:

I was brought up to the ward n they just plugged me into machines. (*Allison*)

Most participants also described times when they had not fully understood medical procedures yet complied without complaint. This is illustrated in Max's description of family conversations with medical staff about his imminent transplant.

M: Aye, there was a lot of stuff I didn't understand (...) I was like... "I dunno... what are they talking about?"

E.W. [interviewer]: Mmhm. Mmhm. Looking back... what kinda things did you not understand?

M: All these complicated things they were talking about. I didn't know what they were talking about (...) I just thought, I better just do what I'm told. (*Max*)

Missing out on life

All participants explained that they had felt they were missing out on life whilst awaiting their transplant. All participants experienced their pre-transplant lives as a time of feeling different from peers and excluded from routine social activities as a result of their ill-health as illustrated below:

E.W.: You didn't feel the same as your friends?

M: No. I mean I was missing out... I felt like I was missing out. (...) Like they were doing stuff and I wasn't there. (...) They went swimming... they went everywhere... but I was just too tired. (*Max*)

Here, Max's repetition of "I was missing out" reinforces how excluded he felt from activities his peers were enjoying. In addition, the statement "they went everywhere" exaggerates the movements of his peers in so emphasising how trapped he felt in comparison.

Ben, Josh and Allison had received dialysis treatments before having their transplant and described these as having limited their ability to lead a “normal” life. For example all three had haemodialysis and explained that this treatment had necessitated hospital visits three times each week, which prevented them from engaging in everyday activities such as going to visit friends. In addition they also said that during the procedure they were attached to a haemodialysis machine for several hours, which was uncomfortable and meant they could not move freely. Those who received peritoneal dialysis explained that this treatment had the benefit of being home-based but they still had to be attached to the dialysis machine for extended periods, which reduced their ability to participate in routine and/or social activities in the evening. Allison described her experiences of haemodialysis and peritoneal dialysis as follows:

- (i) It was uncomfortable [*haemodialysis*]. One of the tubes kept getting blocked so it was quite sore. It was really, really uncomfortable. You’d start getting cramp... you cannae move cos it’ll set off the alarm for the machine. (*Allison*)
- (ii) It takes twelve hours [*peritoneal dialysis*]. (...) I needed to go to my bed really, really early so that it would be finished in time for school (...) I couldn’t stay out as long as my friends could cos I always had to go on the machines and that. (*Allison*)

Finally, all participants described significant disruption to their ability to engage with school life before having their transplant. This resulted from either intense pre-transplant fatigue or the need for frequent hospital-based haemodialysis sessions. Every participant reported that they had missed classes and important schoolwork, sometimes over several years:

I used to be on dialysis and I would miss a lot of school because I would come up here about three times a week... It was Tuesday, Thursday and Saturday. After it I’d get tired, you know. I’d just have to go home after it... I missed quite a lot of P6, P7, 1st year, and 2nd year. I missed quite a lot of them. (*Josh*)

Restrictive self-care behaviours

All participants had to adhere to strict pre-transplant dietary restrictions, which were uniformly experienced as a struggle. Forbidden foods were often items they had previously enjoyed and found hard to relinquish, as evident in the following extract:

- E.W.:* Were there other things that you were looking forward to [*post-transplant*]?
A: Like being able to eat what I wanted (...) ’cos I had gone all that time without eating stuff. (...) You weren’t allowed chocolate... you weren’t allowed tomatoes... you were only allowed cheese once a week... you were hardly allowed anything (...) I went from eating anything I wanted to not being able to eat it [*when I became ill*] (...) It was quite hard... you don’t really understand it, ’cos you were allowed stuff before then you weren’t allowed it (...) Sometimes I’d just go up to my room and lock myself in it ’cos I was angry and upset. (*Allison*)

Each participant also had to adhere to strict fluid consumption limits and described this as a challenging self-care behaviour. All commented on how little fluid they were permitted each day and how difficult it had sometimes been to not exceed this, as illustrated below:

- (i) I was always being told not to drink so much so I was. (*Ben*)
- (ii) My dad kept on saying, "Don't drink a lot!".... and he would give me like about 15ml orange juice. (*Josh*)

Emotional wellbeing

All participants described a lost sense of self pre-transplant, for example Max said:

I didn't feel like anyone... I felt like a tired guy all the time. (*Max*)

In addition, the physical and psychosocial challenges of pre-transplant life (such as overwhelming fatigue and feeling different from peers) appeared to make participants vulnerable to feelings of low mood as exemplified in the following extract:

M: I didn't really like life back then. (...) I felt sad. I felt down.
E.W.: Why do you think you felt sad, felt down?
M: Cos I had no life at all. (*Max*)

Here, Max emphasises the depth of his distress by paraphrasing depressive words in reference to his emotional state, whilst his closing statement communicates a sense of hopelessness and suggests he regarded his pre-transplant quality of life as extremely poor.

The other predominant emotion that participants experienced before having their transplant was fear. All suffered a range of worries pertaining to their pre-transplant medical circumstances and long-term futures. This is captured in the following extract in which Max appeared to find it hard to directly state that he was worried he might die during his transplant operation.

E.W.: Were there any other things you were worried about before you had your transplant?
M: Yeah... in case it went wrong. (...) In case it didn't work out as well as they hoped it would. (...) I had... thoughts.
E.W.: Mmhm... what kind of thoughts?
M: Dying... I could die. (*Max*)

It was noteworthy that most participants described the final hours preceding their transplant operations as a period of emotional turmoil when fears about the procedure mixed with positive feelings related to the improved quality of life participants expected post-transplant, as illustrated below:

I was like happy but I was scared and nervous too... (*Allison*)

Although most participants reported that they had experienced challenging pre-transplant emotions, one claimed to have experienced no such feelings:

E.W.: How did you feel before your transplant?

B: Pretty happy really. Felt happy with myself. (*Ben*)

At other points in his interview Ben described very difficult pre-transplant experiences, such as peer rejection, that seem incongruent with feelings of happiness. Ben presented as emotionally flat across his interview and never spontaneously described his feelings.

Coping [Theme B]

Cognitive coping strategies

All participants used a range of cognitive coping strategies to help them manage worries about situations they could not alter across the kidney transplant process (e.g. fears about starting dialysis; fears their transplant operations could go wrong; fears about their post-transplant vulnerabilities). These strategies differed between participants but included minimization, avoidance, humour, denial, positive thinking and challenging unpleasant thoughts. Applications of these cognitive coping strategies are illustrated in the following quotes:

- (i) I just forget about it really [*worries about the need for another transplant in the future*] and think about the next day... just kind of wipe it off my shoulder. That's it really. (*Allison*)
- (ii) I'd just think that I'd be back to normal. Kept thinking positive. That's what I always do. (*Josh*)
- (iii) *E.W.:* When you were having that think about it [*the forthcoming transplant operation*]... what thoughts went through your mind?
M: Well you're getting this operation, you'll have to trust these doctors, that's what they're here for, they wouldn't do anything to hurt you, they're here to help, you need to trust them and get on with it. (...) Trust the doctors. (*Max*)

Instrumental coping strategies

Most participants employed instrumental coping strategies to help them manage the practical challenges of kidney transplantation such as mobile phone alarms and pillboxes to remind them when to take their medications. Participants said these approaches offered control over their self-care behaviours as illustrated below:

I just like... I wake up... and I say to my dad I need to take like 700ml... that's a big bottle right... and then when I need to, I fill it up... and I put it all on a wee board. (*Max*)

Support from others

All participants described significant positive aspects to the parental care they had received throughout their transplant journeys. Each explained that their parents' had provided considerable practical support. For example, Josh's father left his work to care for him when he became ill. Every participant described comfort in their parents' emotional support. This is clearly illustrated in Max's reflection of the night before his transplant operation:

It was good to have them. (...) I couldn't have sat there myself! (*Max*)

Nonetheless, all participants described their parents' attempts to offer support as overprotective at times. For example, participants found it hard when their parents gave frequent prompts to follow self-care behaviours or adopted a high level of control in their post-transplant lives. This is captured in Allison's account of feeling overprotected by her mother's high level of supervision during her early post-transplant life.

She'd always be keeping an eye on me (...) telling me to be careful all the time... that I would hurt myself and all that (...) She didn't really like me going out unless she was with me. I think it was because she was always scared that something bad was going to happen when she wasn't there (...) It was hard... I just wanted to be treated normal. (*Allison*)

As well as parental support, all participants described the helpful emotional support they had received from medical staff. For example, how comforting nurses' support had been immediately before the transplant operation:

The nurses... They just kept on smiling! They just kept on saying "be positive"... "When your kidney goes in, you will be back playing football again"! (*Josh*)

Nonetheless, all participants noted that the support behaviour of medical staff could sometimes be challenging, in particular their self-care prompts as illustrated below:

E.W.: What would you tell other young people to expect before they had a kidney transplant?
B: To just really expect to constantly get moaned at really... to drink more and to always take your tablets.
E.W.: Who does the moaning?
B: Mmm... X [*member of renal team*] and ma mum (*Ben*)

Across the participants' accounts, siblings were cited as an important source of emotional support. Participants described how their siblings cared for them, how their siblings offered them a sense of normalcy when ill, and how they sought their siblings as confidants with whom to share worries. For example, Allison discussed how comforted she felt by her brother's support as illustrated below:

That actually helps though, when he jokes about it. I know he'd be there for me if anything's wrong. (*Allison*)

Nonetheless, there were times when sibling support was experienced as unhelpful. For example Allison described how difficult she found it when her brother became protective of her immediately following her transplant when she really wanted to be treated as 'normal', whilst Josh described difficulty accepting his siblings' attempts to monitor his pre-transplant restricted diet:

Instead of me watching out for them, they would watch out for me like... "you're not allowed to eat this"... or "you're not allowed to eat that". (...) That was quite hard. I would just eat it anyway. (*Josh*)

Allison, Max and Josh experienced the support of their friends as a valuable coping strategy. Across their transplant journeys these participants sought the normalcy and acceptance of being included in their friends' activities. Their friends' support helped them cope with feelings of solitude when ill and with thoughts of being different because of their transplant. For example, Allison discussed how she disliked haemodialysis but felt uplifted when her friends came to visit her in hospital during this treatment, while Max recalled how he had appreciated his friends treating him the same as they had always done when he was unwell:

- (i) ... they would come up on a Saturday... and that helped. (*Allison*)
- (ii) ...they did help... I never really bothered... they never really bothered... they treated me just the same. (*Max*)

On the other hand, all of the participants also said that they preferred not to discuss their transplant experience in detail with their friends. Allison had experienced a time when her friends had asked her very personal questions about her transplant, which she experienced as intrusive. In addition, Josh described his friends as having adopted a parental role in monitoring his self-care behaviours that he appeared to find difficult at times:

When you go on holiday with them, they say "Bring your medicines.... how many have you got? did you drink enough?" ... They're like my Dad sometimes! (*Josh*)

Finally, Allison and Josh discussed how much they appreciated the support of other young kidney transplant patients and how this prevented feelings of isolation.

... we were on the same dialysis team... we used to watch out for each other... you know what I mean? We used to talk about how much we were drinking... (*Josh*)

Allison, Josh and Max all explained that other kidney transplant patients were a source of inspiration and the only people who fully understood their experiences:

- (i) I was reading in a magazine about this lady who got a transplant when she was about twenty. She's still got it just now and she's like... I think she's like forty. Twenty years! That's quite good. She took care of it. It can last up to thirty years if you take care of it. So that's what I'm trying to do. (*Josh*)
- (ii) It does help... meeting someone else who actually knows what you've been through. They understand it. You don't feel so alone. (*Allison*)

Post-transplant adjustment [Theme C]

Medical requirements

All participants experienced their unrestricted post-transplant diet as a positive new freedom, as illustrated below:

Like the eating. You can eat really whatever really now... high potassium foods... at least that's what happened with me anyway n like now I can really eat just whatever. *(Ben)*

Ben, Josh and Allison also experienced the end of dialysis treatment as a positive change that allowed them to feel more "normal":

No more dialysis for me! I'm normal now... I'm normal! *(Josh)*

On the other hand, Ben, Josh and Allison experienced an increase in their medications post-transplant and described adjustment to this as challenging. Ben and Josh, reported that they had expected this change but had found their new regimens harder to adapt to than they had anticipated. In contrast Allison said that she had actually expected a significant decrease in her medications. She thought that her post-transplant adjustment had been impeded by not knowing that her medications would increase in advance of it happening:

I had only just learned to swallow tablets and some of these were massive ones... and I was like "I cannae get them down my throat!"... 'cos they were sticking. (...) They had a few words for me 'cause I didn't want to take them. (...) You just felt that you wanted to give up 'cos... like... you had to take them all the time (...) I think if they'd told me how many tablets I was going to be taking... I think that would have made it a bit easier for me... I didn't understand... It would have been easier if I'd known. I'd just thought "you'll need to take some tablets after this" but they'd never actually said how many or how many times a day. *(Allison)*

Max was the only participant who experienced an unexpected decrease in his medications post-transplant. He perceived this as having considerably enhanced his quality of life:

(...) well there was more tablets before but I thought it would be the exact same tablets... but I only take three sets of tablets now. (...) *[It was]* A surprise. (...) It was great. *(Max)*

All participants were aware of the risks inherent in missing their post-transplant medications.

Thoughts about forgetting medications were experienced as very frightening:

Negative thoughts about not taking my medicines.... just like... "Did I take my medicine? Did I not? I probably did take it. I don't know". (...) Like sometimes you forget it like. It's sometimes too much... and then you're out sometimes and forget... then it's... "Did I take them, or, did I not?"... and you don't want to overdose you know? (...) That normally like, makes me nervous. Like sometimes, I go on the internet... "What happens if I overdose on this?"... So I see stuff there. *(Josh)*

Nonetheless all participants reported that there had been times when they had found it difficult to remember to take their medications, particularly when they had been out socialising with their friends.

E.W: So what are the tricky bits?

M: Remembering the tablets... remembering to take the tablets... cos you might be busy, you might be out with your pals and then you're like "oooh, where are they tablets?!". (*Max*)

To protect the health of their transplanted kidneys all participants had to drink several litres of water a day post-transplant, which was a significant change from their pre-transplant fluid restrictions. Allison had not expected this new self-care behaviour before receiving her transplant and she believed this made her post-transplant adjustment harder. The other participants explained that although they had known what their post-transplant fluid consumption requirements would be, it was harder to meet them than they expected. This is illustrated in the following extracts:

(i) Like constantly having to drink... like *having* to drink... you have to like drink three and a half litres n sometimes that can be kinda difficult. (*Ben*)

(ii) It was just drink, drink, drink. It was quite hard. (*Josh*)

Post-transplant, it was important for all participants to avoid activities that could endanger their transplanted kidney. Josh and Max routinely engaged in sporting activities post-transplant and said that they had felt vulnerable when others played rough. For example, one of Max's hobbies is boxing training. Here Max describes how his brother had attempted to engage him in sparring practice at home following his transplant and how he had to tell his brother to stop as he feared he might die if his brother hit his transplanted kidney:

He used to play about... and I had to just say to him "X [brother's name]... I've got a big scar on my belly... you hit that... n bye, bye Max". (*Max*)

Education

All participants' school attendance increased post-transplant which they uniformly described as a positive change:

...before I was missing quite a bit of it so I was... whereas like, once I got it I was there every day mostly. (...) It was good. (*Ben*)

Nonetheless, Ben and Allison could not recall exactly when they left school despite this significant life event having occurred within the last year. Furthermore, both Max and Allison acknowledged that their kidney transplant had not completely removed their school-based difficulties. For several

months after his transplant, Max had to complete additional work to catch-up with his peers academically:

M: Aye... I had to catch up this year... I had to catch up cos I'd missed most of first year.

E.W: Were you worried about school?

M: Aye... whether I'd get kept back in first year. (*Max*)

Allison believed that her education had never recovered from the damage of high pre-transplant school absenteeism. She said that she believed this had negatively impacted her academic qualifications and long-term vocational opportunities:

I don't really think I was educated. (*Allison*)

Relationships

All participants described pleasure in the possibility, or actual attainment, of greater independence from their parents post-transplant. They all discussed how this related to a desire for less parental supervision, a wish for more freedom in their social lives, and the hope for new opportunities to develop their autonomy. This is illustrated in the following extract in which Max explained that he hoped to learn how to organise his own medications within the next year:

I'd love to help myself (...) so that my mum and dad don't need to always be there to look after me... being more grown up. (*Max*)

Max, Josh and Ben discussed how their parents were generally supportive of their transition towards greater independence, although each highlighted that parental prompts to adhere to self-care behaviours could still be challenging. One divergence in the data was that Allison unexpectedly found that her parents became significantly *more* protective following her transplant in a manner she experienced as very challenging:

They were all wrapping me up in cotton wool and it just got so annoying! (...) I thought they'd just treat me like they normally did. Just the same. It hit me with surprise! I was like "woaah, calm down!" (*Allison*)

All participants also reflected on their post-transplant peer relationships and described a conflicted sense of being both "the same as" and "different from" their friends. Each reported that they felt more like their peers due to an increased ability to engage in social activities. They described this change as positive. Nonetheless, participants' self-care behaviours and medical histories served as reminders that they remained different from their friends, which they sometimes found challenging.

I can do most of the same stuff as them now. But they sometimes remind me to drink as well. (*Josh*)

Emotional adjustment

Ben, Josh and Max reported that since receiving their transplant they had felt happier and more confident:

I just felt good. The moment... That first day when I was still in bed... I was thinking, "Wooaw", a great feeling... I was back to normal. I didn't feel knackered anymore. *(Josh)*

In contrast, Allison reported that she had suffered several periods of emotional distress post-transplant. She explained that she did not have a well-developed understanding of kidney transplantation until the week after her operation when her mum fully explained the procedure she had undergone for the first time. Allison had not expected to be told that her new organ came from a deceased donor, a fact which she found difficult to accept:

I felt horrible. I used to think how I had someone else's son's or daughter's parts inside me and I just felt pure horrible. *(Allison)*

Allison said that she had worked through this early period of distress with a counsellor's support. Nonetheless, she reported that she had recently begun to experience distressing thoughts again, this time pertaining to the lifespan of her transplanted kidney and to the possibility that another person may have died awaiting a transplant when she received hers:

Sometimes you get quite down. Like I sometimes feel quite sad because someone else could have got that kidney instead of me... and they could have died waiting for it. That makes you feel quite down sometimes. Quite guilty. *(Allison)*

Thoughts about the kidney donor

All participants had received deceased donor kidney transplants. For Josh and Allison, thoughts about their donor were dominant as they adjusted to their post-transplant life. Both expressed a desire to know more about their donor:

They just said where he was from, that he had passed away and that he's given you a kidney to use so take care of it. That's all they said... but I wanted to know more you know? *(Josh)*

Both also experienced thoughts about how the possession of another's kidney might alter the integrity of the self:

I thought whoever... whatever the guy did... I'll do the same. You know... 'cause it's his organ. That whatever he did... I'd do the same. But that's your heart. You do what you want to do... it's not about the kidney. (Josh)

Here, Josh describes his initial worries that he would adopt the persona of his kidney donor and no longer retain full control over his actions. Josh appears to have resolved these worries by reasoning that the heart contains a person's soul. In contrast to Josh's experience, Allison felt that there *had* been a merging of selves between her and her donor:

A: I remember I got a scan of my kidney not that long ago and there was a face on it... and I've been wondering since then... if that was maybe his face. (...) Like it's always haunted me since then... if it was his face that was on it [*her transplanted kidney*].

E.W.: Do you feel like you have a relationship with him?

A: Aye. Cos like, there's some things that I used to never like... that I like now. I always wonder if they're things that he used to like. Sometimes you hear that... that if you get a transplant a part of them [*the donor*] is with you. That you'll like things you didn't before. That you'll stop liking things you used to like. (Allison)

Meaning of transplant

The participants ascribed multiple positive meanings to their experience of having a kidney transplant. All participants highlighted that their transplants symbolised an escape from unpleasant medical procedures or death:

M: I could have been... [*draws line across his neck with his finger*]... right now.

E.W.: You could have been dead?

M: Yes... no life... dead... or maybe not, I might have been on dialysis right now. (...) I was just about to start dialysis. I wouldn't have liked that. (Max)

Transplantation was also described by Allison, Josh, and Max as a transformation. The participants explained that their transplants had given them the possibility of a future that contrasted sharply with the struggles they had suffered pre-transplant. This is captured below:

It makes me feel like I've been reborn. (...) You wake up every morning and you feel absolutely great. (Allison)

All participants reported that their transplant had bestowed them with the chance “to be normal” and to feel more akin to their peers. This was illustrated by Josh who compared the effect of his transplant to being enrobed:

Before your transplant it’s like everybody else has clothes and you’re a little bit naked... but after your transplant... you have clothes as well. Clothes like everybody else. You can do the same as everyone else. Normal. (*Josh*)

It was also noteworthy that Allison, Max, and Josh all described transplantation as a vivid time. They explained that their memories of the events immediately before and after their operations had remained very clear despite the passage of time:

E.W.: Does it feel like a long time since you had your transplant?

J: No. It feels like last week. (*Josh*)

In contrast to this, Ben described his transplant operation as a vague time and seemed to have difficulty recalling whether it had taken place earlier this year or the year before:

It was a couple a days before ma birthday so it was. So it was... I think I must a been coming up for seventeen I think... possibly... either that or coming up for sixteen... one of them. (*Ben*)

Expectations

All participants had experienced multiple pre-transplant expectations about how their life would change post-transplant. For example, each believed that they would feel less tired and be able to do the same social activities as their friends. All participants’ pre-transplant expectations were positive and linked to the more general belief that life would become “normal” post-transplant:

(i) Not feeling tired all the time... being able to eat all the foods that I wanted and that... and having more energy... and just being me! (*Max*)

(ii) I just thought that I’d get the kidney and the next day I’d be out. That I’d just be normal... (*Allison*)

Max, Ben, and Josh reported that their pre-transplant expectations had been fulfilled. Despite this they all described feeling different from their peers in some ways post-transplant. In addition they all discussed difficult post-transplant experiences that they had not anticipated and which they regarded as important for future transplant candidates to be informed of in order to help them better prepare for post-transplant life. For example, Josh felt that others should be forewarned that

they would have tubes attached to their bodies for a period of time immediately after their transplant operations:

... nobody told me I'd have tubes and that was a real shock. *(Josh)*

In contrast to the other participants, Allison acknowledged that some of her pre-transplant expectations had been inaccurate. She said that this had caused her distress and impeded her post-transplant adjustment. She felt that if she had developed a better understanding of kidney transplantation before undergoing the procedure, she would have found it easier to accept her new kidney and the self-care behaviours she was required to adhere to post-transplant:

I think that if I'd got it when I was older, I would have expected those things a bit more. I would have understood things better. *(Allison)*

DISCUSSION

This study aimed to build a comprehensive understanding of young people's lived experience across kidney transplantation. Most participants remembered times they had felt objectified when awaiting their transplant and recalled compliance with procedures they did not understand. Feeling objectified might stem from the focus on control of the body that occurs in medical settings and communicates a perceived neglect of individuals' idiosyncratic emotional experiences, whilst the acquiescence described raises questions about how to ensure young patients' informed consent to treatment (37). Consistent with previous studies all participants felt pronouncedly different from other young people, and excluded from social activities, before receiving their transplant (38; 39). All of the participants' pre-transplant expectations were linked to the general belief that life would become "normal" post-transplant. Most participants reported complete fulfilment of their expectations, yet contradicted this in describing a conflicted sense of being both "the same as" and "different from" their peers post-transplant. This feeling was rooted in the paradox of being able to engage more fully in "normal" everyday activities, whilst simultaneously facing self-care behaviours and medical histories that operated as challenging reminders of their continuing ill-health status. It seems adolescent patients may find it psychological threatening to acknowledge unmet pre-transplant expectations signifying they are "different" from peers (40). This possibility is bolstered by the high value participants consistently placed upon assimilation with peers in this study, a typical drive at this developmental stage (13). Interestingly, one participant reported their pre-transplant expectations *had* been markedly inaccurate. They said this had not only caused them considerable distress post-transplant, but also impeded their ability to accept their donor kidney and new self-care behaviours.

Consistent with previous investigations, all participants showed a vulnerability to educational difficulties across the transplantation process (41). A recent review noted there are no clear guidelines on how to best support the educational needs of paediatric patients with chronic kidney disease despite their well-documented risk of academic problems (42). This difficulty must be addressed given that all young people have the right to an education and that research shows an education in one's youth is associated with the attainment of healthy self-esteem, and a high quality of life, in adulthood (43; 44; 45).

Another key finding was that all participants experienced their pre-transplant dietary and fluid consumption restrictions as significantly challenging. To our knowledge this is an unexplored area of adolescent patients' pre-transplant lives, although these self-care behaviours have been linked to the development of depression and anxiety in adult patients (46). Post-transplant, the removal of dietary restrictions prompted positive feelings. Nonetheless medication increases were described as a challenging experience that could be hard to accurately envisage pre-transplant, which is consistent with the ongoing development of the prefrontal areas of the brain during adolescence (16; 17). In addition, most participants also described some difficulties in remembering to take their medications post-transplant, particularly when socialising with peers. This supports the previously documented high-risk of medication non-adherence in adolescents following transplantation, and also suggests there may be specific times when this vulnerability is heightened (12). It was noteworthy most participants also experienced their increased fluid consumption requirements as unexpectedly challenging post-transplant. This issue has not been investigated before in adolescent patients, but these findings are consistent with research suggesting adult patients find this self-care behaviour difficult to self-monitor (47). Post-transplant, activities that could endanger a donor kidney must be avoided. This instigated feelings of vulnerability in those who routinely completed sporting activities. To our knowledge no other studies have explored this particular self-care behaviour, which is an important literature gap given that engagement in activities such as sport can significantly influence adolescents' health and psychosocial wellbeing (48; 49).

In harmony with prior studies, most participants experienced low mood, fear, and "a lost sense of self" pre-transplant (50). Although "identity loss" has previously been identified as a common vulnerability in paediatric dialysis patients, one participant reported this difficulty despite having never received dialysis (38). This suggests patients' self-identity may already be compromised by their illness experiences before the onset of dialysis. One commonality the participants shared was emotional turmoil in the final hours preceding their transplant operations. Fear predominated this time but was mixed with positive feelings about the benefits participants anticipated post-transplant. This highlights the significance of pre-transplant expectations in installing hope at this stage of patients' transplant journeys. Post-transplant, most participants reported feeling happier and more confident. Nonetheless, one participant did openly admit to having suffered marked emotional distress post-transplant. This participant was female, whereas all others in the sample were male, so one possibility is that this divergence might reflect a gender-based difference in the experience of kidney transplantation. Research suggests the prevalence of anxiety and low mood tends to be higher in females, although there is also evidence showing males find it harder to admit to these experiences (51; 52; 53). Interestingly, two participants reported that thoughts about their kidney

donor were dominant as they adjusted to post-transplant life. Both desired more knowledge about their donor and expressed fears about how the possession of another's kidney might affect the integrity of the self. Research into the psychological process of organ integration is currently in its infancy and as such it is still not well understood. All previous studies have focused on adult patients but their findings suggest similar concerns are also experienced in this population (54; 55).

A range of cognitive coping strategies, such as minimization, were used to manage the difficult feelings that arose across participants' transplant journeys. Furthermore most also utilized instrumental coping strategies, such as memory prompts, to address the practical challenges they faced. These findings are consistent with the two discrete types of coping proposed in "The Transactional Model of Stress and Coping": (i) '*emotion-focused coping*' – aimed at regulating psychological distress in situations beyond personal control (e.g. distraction to reduce anxious thoughts about the risks of surgery); and (ii) '*problem-focused coping*' – aimed at finding practical solutions to stressors that *are* within personal control (e.g. instrumental diaries to log fluid consumption) (56). It is noteworthy that the participants' cognitive coping strategies included denial, avoidance, and emotional numbing. These can be adaptive in the short-term but their extended use is associated with a more marked and protracted neuroendocrine stress reaction, and they appear to heighten the risk of mental health difficulties following traumatic experiences (57; 58; 59).

Consistent with earlier studies, all participants described beneficial aspects to the support they received from others (29; 41; 60; 61). Positive social support appears to modulate the neuroendocrine stress reaction by influencing oxytocin and cortisol levels, in so leading to a reduction in stress (62; 63; 64; 65; 66). Previous research suggests positive social support is associated with higher levels of self-esteem, and a lower risk of depression, in adults with chronic health difficulties (67). Despite the identified benefits of social support, participants consistently found it hard to cope with persistent parental prompting to follow self-care behaviours and high levels of parental control in their post-transplant lives. Previous research suggests that when young people have a chronic illness, parental overprotection increases their risk of behavioural difficulties and impedes their ability to develop age-appropriate levels of independence (68; 69; 70). Interestingly, the participants in this study also reported that siblings, healthcare staff, and friends also issue challenging self-care prompts post-transplant.

Consistent with the experiences of adult patients, all participants ascribed their kidney transplant with positive meanings (e.g. “a chance to be normal”) (71). Although most described the period immediately surrounding their transplant operation as a “vivid time”, one recalled it as very vague. Research suggests paediatric kidney transplant patients may be at increased risk of cognitive deficits (72; 73). This could account for the participant’s vague recollections. Nevertheless, adult patients have described transplant surgery as a trauma experience, and the participant with vague recollections presented as emotionally numb at interview (74). This is a common trauma symptom, suggesting this to be an alternative explanation for their presentation (75; 76).

Clinical Implications

The powerless feelings and acquiescence participants' described pre-transplant, raises questions about how to ensure young people's *informed* consent to chronic kidney disease treatments. The National Institute for Health Care Excellence (NICE) 'chronic kidney disease' guidelines stipulate the need to include young people in decision-making and to share information in developmentally accessible ways (77; 78). All participants had received a pre-transplant work-up to help them prepare for surgery, making these findings somewhat surprising. They suggest new strategies are needed to empower adolescent patients, and to help them develop a deeper understanding of the medical procedures to which they give their consent pre-transplant (79). In addition, given the isolation participants described, it seems there could be benefit in helping adolescents access more social opportunities pre-transplant. A web-based virtual community has recently been found to increase American paediatric transplant patients' feelings of normalcy; there could be value in testing this intervention approach more widely (61). Educational difficulties were also problematic from the pre-transplant stage of all participants' transplant journeys. This indicates value in testing new strategies to help adolescent patients' maintain their studies (e.g. video conferencing to allow the experience of a virtual classroom), and in trying to develop new guidelines around this issue.

Given the evidence suggesting that young people find it difficult to acknowledging unmet pre-transplant expectations that signify they are "different" from peers, it seems pertinent that healthcare staff remain vigilant for minimisation of psychosocial difficulties during adolescents' post-transplant assessments (40). In addition, the challenges that were associated with unrealistic pre-transplant expectations suggests some young people would profit from targeted help in developing more realistic expectations before receiving their transplant (e.g. about the challenges they will experience in adjusting to changes in their post-transplant medications). The participants also uniformly showed a vulnerability to mental health difficulties across transplantation, including organ integration fears. This supports the need for clinical psychologists to be embedded within multidisciplinary paediatric renal teams to offer expert assessment and intervention work at all stages of patients' transplant journeys (42).

In addition, the present study suggests that some adolescents would benefit from support to manage their self-care behaviours (e.g. fluid consumption targets). It is noteworthy that most participants felt harried by others who issued self-care prompts and by "overprotective" parental behaviours in their post-transplant lives. This suggests utility in exploring how self-care prompts could be made to feel less intrusive (e.g. by assessing different modes of cue delivery), and investigating whether systemic

intervention approaches could promote young people's post-transplant adjustment by impacting family dynamics (e.g. the provision of family therapy) (80). Research shows chronic exposure to stress hormones adversely impacts brain development, and that coping strategies become more rigid in adulthood (81; 82; 83). Given that paediatric kidney transplant patients are vulnerable to stressful medical challenges throughout their lives, and that the participants in this study managed their difficulties in ways that can be maladaptive longer term, it seems important for health care staff to help adolescent patients build robust toolkits of adaptive coping strategies.

Future Research

Inaccurate pre-transplant expectations were found to negatively impact some participants' post-transplant adjustment, but additional studies are necessary to develop a deeper understanding of this relationship. For example it would be beneficial to investigate whether age at transplant affects the accuracy of young people's pre-transplant expectations given the expansion in cognitive skills seen across adolescence (which could allow a more comprehensive understanding of transplantation to be developed before undergoing the procedure) (13).

Further research is also needed to identify the variables that increase young people's risk of emotional distress across transplantation; in order to aid the early identification of those most at risk of these problems. Moreover, the current results suggest value in advancing research into the cognitive functioning and trauma symptoms of young kidney transplant patients to ascertain whether they have an underlying vulnerability to difficulties in these areas. In addition, this was the first study to verify that organ integration processes affect the fluidity of adolescents' psychological adjustment post-transplant. Additional research in this area is crucial. For example there is growing evidence that having a very close psychological relationship with one's deceased donor, is associated with an increased risk of psychological distress and medication non-adherence in adult patients (84; 85; 86). It would be valuable to explore whether parallel effects exist in paediatric populations. In addition, one of the main developmental goals of adolescence is to build self-identity (10). Experiencing existential questions about the integrity of the self is likely to make this process considerably more complex. The interaction between organ integration processes and the development of young people's self-identity is therefore another important area for future research.

Adolescent patients' vulnerability to medication non-adherence has been robustly established in prior investigations (10). The current study builds on earlier research in finding that some participants knew they were more vulnerable to medication non-adherence when socialising with peers. It would be beneficial for future studies to explore whether there are other times when this vulnerability is heightened, and the reasons why socialising with peers constitutes such a high risk time for some patients. For example socialising with peers might increase young people's forgetfulness or alternatively make them fear peer rejection for standing out as "different", each of which would indicate different intervention approaches. The results of the current study also highlight how challenging other self-care behaviours can be for young people across kidney transplantation. This suggests it would be helpful to investigate how adolescents' broader repertoire of self-care behaviours impact on their mental health, and what factors influence their ability to cope with these demands.

More research is also needed into how young patients' cognitive and instrumental coping strategies affect their emotional wellbeing across kidney transplantation. When conducting this work, the role of coping strategy maturation should be considered as cognitive development increases young people's range and complexity of coping skills (26; 87). Furthermore, previous studies report a positive association between the length of time paediatric patients receive dialysis and the extent to which they rely on adult support; which suggests value in investigating the impact of treatment history on patients' coping strategies (88). In addition, it would also be beneficial to gain a deeper understanding of how differences in interpersonal relationships affect adolescent patients' coping capacities (89; 90). Future research in this area would benefit from the adoption of an attachment focus as young people's attachment styles are likely to play a significant role in shaping their ill-health coping behaviours (90; 91). For example, when a child's primary caregivers are consistently unresponsive they often learn to suppress their fears and become unusually self-reliant (92; 93). This pattern is described as an avoidant attachment style and is associated with lower levels of medical help-seeking (94). These issues have clear treatment implications in relation to paediatric kidney transplant patients, for instance they indicate potential value in employing attachment-focused interventions such as dyadic developmental psychotherapy (95).

Limitations

One of the key limitations in this study is that all of the participants had experienced deceased donor kidney transplants that had been successful. Nonetheless many young people receive their new kidney from a living donor (e.g. relative), undergo unsuccessful transplant operations, or suffer post-transplant medical complications that result in the loss of their donor kidney (6; 8). These circumstances could lead to very different experiences of kidney transplantation from those identified in this investigation. It is also important to note that a retrospective design was employed in this study, which meant that key data was dependent upon participants' recall of past events (e.g. their pre-transplant expectations). The accuracy of these memories is uncertain and for this reason a longitudinal study with a prospective design would have been stronger. In addition, only one participant was female which prevented in-depth exploration of gender-based differences in the transplant experience. Finally, the participants' interviews were conducted in the hospital where they routinely receive their post-transplant follow-up care and so being in this environment may have negatively impacted their willingness to openly discuss their experiences.

Conclusion

Young people's lived experience across kidney transplantation appears to be characterised by pre-transplant struggles, making post-transplant adjustments, and finding ways to cope with difficult circumstances. Many of the study's findings parallel the results of previous research but there have also been several novel insights into this experience, such as the significance of organ integration processes during young people's post-transplant adjustment. This study also offers preliminary support to the proposition that young people's pre-transplant expectations can play an instrumental role in determining their psychological wellbeing, and adaptation to new self-care behaviours, post-transplant. Several new directions for future research are indicated.

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CHAPTER 3: Advanced Clinical Practice I – Reflective Critical Account

Neonatology: Development in the Unit and Beyond

Abstract

It is important for all clinical psychologists to have a strong understanding of the complex ethical issues that can present in clinical practice and to have the flexible high-level communication skills necessary for working in a variety of settings, with a very broad range of different patient and staff groups.

My course 12 advanced clinical practice placement gave me the unique opportunity to work not only in a busy Neonatology Psychology Service, but also in a 'Neurodevelopmental Clinic' that followed-up infants who were at risk due to premature birth over the first two years of their lives.

In this reflective account I work through several important learning experiences from this placement that have fostered growth in my clinical knowledge and skills within the areas of ethical practice and communication. First, I reflect on one experience with ethical significance and one experience with communication significance from my work in the Neonatology Psychology Service. I then move on to reflect on one experience of each nature from my work with cases drawn from the 'Neurodevelopmental Clinic'. Three models of reflective practice are used to structure the reflective process. I then conclude by offering a reflective review of the account. This section considers the highlighted learning experiences in relation to relevant policies, guidelines and legislation. Time is also spent reflecting on how I have developed as a clinician since my first year in training before final thoughts are shared on the importance of reflective practice.

CHAPTER 4: Advanced Clinical Practice II – Reflective Critical Account

The importance and complexity of teaching skills in clinical psychology practice

Abstract

An integral part of the clinical psychologist's role is training others. This is clear with reference to the "Standards of Proficiency" for practitioner psychologists that have been set by the Health & Care Professions Council (2012). The clinical psychologist faces a broad range of teaching responsibilities that demand thoughtful application of complex clinical skills. Doctoral training has allowed me to significantly broaden my understanding of clinical psychologists' teaching role, and has afforded me greater insight into the significance of interpersonal dynamics and process issues when engaging in this kind of work. In this account I have chosen to reflect on this developmental trajectory by exploring two key learning experiences that occurred in my final year of training. The first is my experience of teaching parents about Autism Spectrum Disorders (ASD), whilst the second is my experience of training healthcare staff from other disciplines about the role of a clinical psychologist. Three models of reflective practice are used to structure the reflective process. I then conclude by offering a reflective review of the account. This section considers my experience of completing the reflective account; it considers how the account has aided my development as a clinician; it considers my learning experiences in relation to relevant policies and guidelines; it considers "reflective practice" as an independent clinical tool; and it considers how I will continue to use reflective practice, and my new training insights, as I move forward in my clinical career.

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APPENDIX 1: Author's Guidelines for Submission to Transplantation



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Main Body: Introduction. The introduction contains a statement of the purpose of the work, the problem that stimulated it, and a brief summary of relevant published investigations. Results. The results should be concise, avoiding redundant tables and figures illustrating the same data. Discussion. This section should interpret results, with minimal recapitulation of findings. Materials and Methods. Avoid detailed description of previously published methods and cite the appropriate reference. Detailed methods may be provided as Supplemental Digital Content and will appear in the online version only.

Acknowledgments: This section normally includes sources of research funds, the names of collaborators who are not listed as co-authors, or of any others who contributed to the manuscript. Where a medical writer or editorial assistant has been used to write or edit the article, the writer must be identified and named, together with the source of funding.

References: References should begin on a separate page and numbered in the order in which they are cited in the text, where they are designated by full-sized numbers in parentheses. Only published works and manuscripts that have been accepted for publication should be listed in the References. Manuscripts in preparation, unpublished observations, and personal communications should be referred to in parentheses in the text. Completed manuscripts submitted for publication may be cited as footnotes to the text. If these are subsequently accepted, the author may transfer them to the reference section in galley proof. References Format. No more than six authors should be listed. If there are seven or more, only the first three followed by “et al.” should be included. Titles of journal articles must be included, and abbreviation of journal names should conform to the Index Medicus style.

Tables: Photographs are not acceptable. Type each table, double-spaced through- out (including column headings, footnotes, and data), on a separate page. Tables may be included as part of the Main Body file. Number the tables in sequence in Arabic numerals and supply a concise, informative title for each one. Each column in the tables should carry a concise heading describing the data in the column. Use lowercase superscript letters to designate footnotes, and type the footnotes below the tables to which they refer. Tables are cited in the text in numerical order. Each table should be able to be understood without consulting the text.

Figures and Legends: Figures uploaded with the initial submission are used for the peer review process only, and therefore do not need to be “production-ready” (i.e., with the resolution and file type required for publication). However, if the manuscript is accepted, the figures will need to be prepared in an acceptable format, as described in the section, Submitting the production-ready version of an accepted manuscript. Legends should be supplied for all figures. They are numbered to correspond with the figures and typed double-spaced on a separate page. Figure legends for any supplemental figures being submitted are to be provided separately.

We strongly encourage authors to incorporate other colors in line drawings, graphs and charts. The axis and labeling in these figures must be in black.

Main Body text of the submitted manuscript. SDC files will be available via URL(s) placed at the citation points within the article and are not copyedited by the publisher; they will be presented digitally as submitted. Note that Journal policies for manuscript submission relating to peer review, patient anonymity, ethics, financial disclosure, copyright, and permissions also apply to SDC. Authors should mask patients’ eyes and remove patients’ names from supplemental digital content unless they obtain written consent from the patients and submit them as “supporting documents” at the time of the manuscript submission.

Format, File Type and Size Requirements: SDC must be provided in one Word or PowerPoint file. Each SDC in the file should have a visual header in the following name format (e.g., “SDC, Figure 1”; “SDC, Materials and Methods”) and a corresponding citation must appear in the Main Body text. Note that SDC is numbered separately from non-SDC material. If providing SDC figure(s), a figure legend should be included on the figure itself. When uploading SDC select “Supplemental Digital Content” as the file designation. For audio and video files, also include the author name, videographer, participants, length (minutes), and size (MB). Video files should be formatted with a 320 _ 240 pixel minimum screen size. For each submission, the SDC file cannot exceed a total size of 10 MB.

APPENDIX 2: Author's Guidelines for Submission to Pediatric Transplantation

Pediatric Transplantation

Author Guidelines

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Edited By: Steven A. Webber, MBChB, MRCP Impact Factor: 1.5 ISI

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(Transplantation); 57/122 (Pediatrics) Online ISSN: 1399-3046



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Title page - containing (1) a concise informative title; (2) names of authors; (3) name of department(s)/institution(s) to which the work is attributed; (4) if the title exceeds 40 characters (letters and spaces): a running head of no more than 40 characters should be provided.

Authors- Names department(s) and institution(s) of all authors. Credit for authorship should be based on: [1] substantial contributions to research design, or the acquisition, analysis or interpretation of data; [2] drafting the paper or revising it critically; [3] approval of the submitted and final versions. Authors should meet all three criteria.

Corresponding author- Name, address, email address, telephone and fax numbers. (Corresponding author should take responsibility for communicating with all other authors and getting their approval for the final version to be published. During online submission corresponding authors can nominate an individual, who may or may not be an author, to assist them with administration of the publication process.)

Author contributions- Recommendation: Include a short description of each authors' contribution immediately before your references. (Examples of categories for authors' contributions: Concept/design, Data analysis/interpretation, Drafting article, Critical revision of article, Approval of article, Statistics, Funding secured by, Data collection, Other.)

Abstract page - A separate abstract page should contain the following: (1) Authors' surnames and initials. (2) Title of manuscript. (3) Title of Journal, abbreviated as in reference list. (4) The word Abstract followed by a summary of the article. (5) 3-10 key words according to Index Medicus. (6) Name and address of the author to whom requests for offprints should be sent.

Introduction - Present the background briefly, but do not review the subject extensively. Give only pertinent references. State the specific questions you want to answer.

Patients and methods/Material and methods - Describe selection of patients or experimental animals, including controls. Do not use patients' names or hospital numbers. Identify methods, apparatus (manufacturer's name and address), and procedures in sufficient detail to allow other workers to reproduce the results. Provide references and brief descriptions of methods that have been published. When using new methods, evaluate their advantages and limitations. Identify drugs and chemicals, including generic name, dosage, and route(s) of administration. Indicate whether the procedures were approved by the Ethics Committee of Human Experimentation in your country, or are in accordance with the Helsinki Declaration of 1975.

Results - Present results in logical sequence in tables and illustrations. In the text, explain, emphasize or summarize the most important observations. Units of measurement should be expressed in accordance with *Système International d'Unités* (SI Units).

Discussion - Do not repeat in detail data given in the Results section. Emphasize the new and important aspects of the study. Relate the observations to other relevant studies. On the basis of your findings (and others'), discuss possible implications/conclusions. When proposing a new hypothesis, clearly label it as such.

Tables - Tables should be numbered consecutively with Arabic numerals. Type each table on a separate sheet, with titles making them self-explanatory.

Illustrations - Figures should clarify the text. Their number should be kept to a minimum. Submit 3 unmounted copies of each illustration, labelled on the back with the number, author's name, and indicate the top of the figure. Figure legends must be typed on a separate page at the end of the manuscript. Figures should be professionally drafted, and halftones should exhibit high contrast. Details must be large enough to retain their clarity after reduction in size. After reduction, illustrations should preferably fill single-column width (81 mm) although in exceptional cases 2/3 page width (120 mm) or full page width (168 mm) will be accepted. Photomicrographs must have internal scale markers (linear scale).

Abbreviations and symbols - Use only standard abbreviations. All units will be metric. Use no roman numerals in the text. In decimals, a decimal point, and not a comma, will be used. Avoid abbreviations in the title. The full term for which an abbreviation stands should precede its first use in the text unless it is a standard unit of measurement. In cases of doubt, the spelling orthodoxy of *The Oxford English Dictionary* will be adhered to.

References - These should be kept to the pertinent minimum and numbered consecutively in the order in which they appear in the text. Identify references in text, tables, and legends by Arabic numerals (in parentheses). References cited only in the tables or figure legends should be numbered in accordance with a sequence established by the first identification of that figure in the text. Try to avoid using abstracts as references. Include manuscripts accepted, but not published; designate the abbreviated title of the journal followed by (in press). Information from manuscripts not yet accepted, should be cited in the text as (submitted). The references must be verified by the author(s) against the original documents. Titles should be abbreviated in accordance with the style used in *Index Medicus/MEDLINE*.

APPENDIX 3: Search Strategy

| Database | Search Terms Used | No. of Papers Identified |
|--|---|---------------------------------|
| MEDLINE | transplant*, expect*, belief, hope, optimis*, pessimis*, renal, kidney, liver, heart, lung, stem cell, bone, marrow | - |
| EMBASE | transplant*, expect*, belief, hope, optimis*, pessimis*, renal, kidney, liver, heart, lung, stem cell, bone, marrow | - |
| Psychology and Behavioural Sciences Collection | transplant*, expect*, belief, hope, optimis*, pessimis*, renal, kidney, liver, heart, lung, stem cell, bone, marrow | - |
| PsychInfo | transplant*, expect*, belief, hope, optimis*, pessimis*, renal, kidney, liver, heart, lung, stem cell, bone, marrow | - |
| CINAHL | transplant*, expect*, belief, hope, optimis*, pessimis*, renal, kidney, liver, heart, lung, stem cell, bone, marrow | - |
| Web of Knowledge | transplant*, expect*, belief, hope, optimis*, pessimis*, renal, kidney, liver, heart, lung, stem cell, bone, marrow | - |
| Cochrane | transplant*, expect*, belief, hope, optimis*, pessimis*, renal, kidney, liver, heart, lung, stem cell, bone, marrow | - |

APPENDIX 4: Quality Assessment Tool

| Crowe Critical Appraisal Tool (CCAT) | |
|--------------------------------------|--|
| Authors | |
| Title of Article | |
| Title of Journal | |
| Date of Publication | |
| Name of Quality Assessor | |
| Date of Quality Assessment | |

| Subscale: Preamble | | |
|--------------------|--|------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Text | 1. Sufficient detail others could reproduce <input type="checkbox"/> 2. Clear/concise writing <input type="checkbox"/> , table(s) <input type="checkbox"/> , diagram(s) <input type="checkbox"/> , figure(s) <input type="checkbox"/> | Preamble Score |
| Title | 1. Includes study aims <input type="checkbox"/> and design <input type="checkbox"/> | |
| Abstract | 1. Key information <input type="checkbox"/> 2. Balances <input type="checkbox"/> and informative <input type="checkbox"/> | |

| Subscale: Introduction | | |
|------------------------|---|--------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Background | 1. Summary of current knowledge <input type="checkbox"/> 2. Specific problem(s) addressed <input type="checkbox"/> and reason(s) for addressing <input type="checkbox"/> | Introduction Score |
| Objective | 1. Primary objective(s), hypothesis(es), or aim(s) <input type="checkbox"/> 2. Secondary question(s) <input type="checkbox"/> | |

| Subscale: Design | | |
|-------------------------------------|---|------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Research design | 1. Research design(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of research design(s) <input type="checkbox"/> | Design Score |
| Intervention, Treatment, Exposure | 1. Intervention(s) / treatment(s) / exposure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Precise details of the intervention(s) / treatment(s) / exposure(s) <input type="checkbox"/> for each group <input type="checkbox"/> 3. Intervention(s) / treatment(s) / exposure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/> | |
| Outcome, Output, Predictor, Measure | 1. Outcome(s) / output(s) / predictor(s) / measure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Clearly define outcome(s) / output(s) / predictor(s) / measure(s) <input type="checkbox"/> 3. Outcome(s) / output(s) / predictor(s) / measure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/> | |
| Bias, etc | 1. Potential bias <input type="checkbox"/> , confounding variables <input type="checkbox"/> , effect modifiers <input type="checkbox"/> , interactions <input type="checkbox"/> 2. Sequence generation <input type="checkbox"/> , group allocation <input type="checkbox"/> , group balance <input type="checkbox"/> , and by whom <input type="checkbox"/> 3. Equivalent treatment of participants / cases / groups <input type="checkbox"/> | |

| Subscale: Sampling | | |
|--------------------|--|------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Sampling method | 1. Sampling method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of sampling method(s) <input type="checkbox"/> | Sampling Score |
| Sample size | 1. Sample size <input type="checkbox"/> , how chosen <input type="checkbox"/> , and why <input type="checkbox"/> 2. Suitability of sample size <input type="checkbox"/> | |
| Sampling protocol | 1. Target / actual / sample population(s): description <input type="checkbox"/> and suitability <input type="checkbox"/> 2. Participants / cases / groups: inclusion <input type="checkbox"/> and exclusion <input type="checkbox"/> criteria 3. Recruitment of participants / cases / groups <input type="checkbox"/> | |

| Subscale: Data Collection | | |
|---------------------------|---|-----------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Collection method | 1. Collection method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of collection method(s) <input type="checkbox"/> | Data Collection Score |
| Collection protocol | 1. Include date(s) <input type="checkbox"/> , location(s) <input type="checkbox"/> , setting(s) <input type="checkbox"/> , personnel <input type="checkbox"/> , materials <input type="checkbox"/> , processes <input type="checkbox"/> 2. Method(s) to ensure / enhance quality of measurement / instrumentation <input type="checkbox"/> 3. Manage non-participation <input type="checkbox"/> , withdrawal <input type="checkbox"/> , incomplete/lost data <input type="checkbox"/> | |

| Subscale: Ethical Matters | | |
|---------------------------|---|-----------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Participant ethics | 1. Informed consent <input type="checkbox"/> , equity <input type="checkbox"/> 2. Privacy <input type="checkbox"/> , confidentiality / anonymity <input type="checkbox"/> | Ethical Matters Score |
| Researcher ethics | 1. Ethical approval <input type="checkbox"/> , funding <input type="checkbox"/> , conflict(s) of interest <input type="checkbox"/> 2. Subjectivities <input type="checkbox"/> , relationship(s) with participants / cases <input type="checkbox"/> | |

| Subscale: Results | | |
|--|---|------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Analysis, Integration, Interpretation method | 1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen <input type="checkbox"/> and why <input type="checkbox"/> 3. Suitability of analysis / integration / interpretation method(s) <input type="checkbox"/> | Results Score |
| Essential analysis | 1. Flow of participants / cases / groups through each stage of research <input type="checkbox"/> 2. Demographic and other characteristics of participants / cases / groups <input type="checkbox"/> 3. Analyse raw data <input type="checkbox"/> , response rate <input type="checkbox"/> , non-participation / withdrawal / incomplete / lost data <input type="checkbox"/> | |
| Outcome, Output, Predictor analysis | 1. Summary of results <input type="checkbox"/> and precision <input type="checkbox"/> for each outcome / output / predictor / measure 2. Consideration of benefits / harms <input type="checkbox"/> , unexpected results <input type="checkbox"/> , problems / failures <input type="checkbox"/> 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) <input type="checkbox"/> | |

| Subscale: Discussion | | |
|----------------------|---|------------------|
| Category Item | Description of Item [<input checked="" type="checkbox"/> Present, <input checked="" type="checkbox"/> Absent, <input type="checkbox"/> Not Applicable] | Score (0 – 5) |
| Interpretation | 1. Interpretation of results in the context evidence <input type="checkbox"/> and objectives <input type="checkbox"/> 2. Draw inferences consistent with the strength of the data <input type="checkbox"/> 3. Consideration of alternative explanations for observed results <input type="checkbox"/> 4. Account of bias <input type="checkbox"/> , confounding / effect modifiers / interactions / imprecision <input type="checkbox"/> | Discussion Score |
| Generalisation | 1. Consideration of overall practical usefulness of the study <input type="checkbox"/> 2. Description of generalizability (external validity) of the study <input type="checkbox"/> | |
| Concluding remarks | 1. Highlight study's particular strengths <input type="checkbox"/> 2. Suggest steps that may improve future results (e.g. limitations) <input type="checkbox"/> 3. Suggest further studies <input type="checkbox"/> | |

| | |
|--------------------------------|-----|
| All Quality Rating Items Score | /40 |
|--------------------------------|-----|

APPENDIX 5: Table of Studies (Articles Identified In The Search Of All Databases Completed On 02/06/13)

| Study and Quality Rating | Sample | Design | Pre-transplant Expectation Measures | Post-transplantation Outcome Measures | Main Findings |
|--|---|--|---|--|---|
| <p>Leedham et al. (1995)</p> <p>– Good Quality</p> <p>[conducted in the USA]</p> | <p>31 adult heart transplant patients</p> <p><u>characteristics:</u></p> <ul style="list-style-type: none"> - 29 males; 2 females - mean age=49.3yrs (range=20-63 yrs) - 29 caucasian participants; 2 non caucasian participants - average time on transplant waiting list=3.6months (range=1-13months) <p><u>inclusion/exclusion criterion:</u></p> <ul style="list-style-type: none"> - must be literate - must be physically well enough to complete the study questionnaires - must be on the transplant waiting list long enough for data collection - must not have had a previous transplant | <ul style="list-style-type: none"> - This study employed a prospective longitudinal design. - Data collection questionnaires were initially distributed when participants were on the transplant waiting list. These were then redistributed when the participants were discharged after their transplant, at 3 months post-transplant, and at 6 months post-transplant. - At all 4 time points, information was also gathered from a single transplant nurse who knew the participants well. | <p>Positive expectations were assessed through a 7-item subscale within “The Quality of Life Questionnaire” that was developed by the research team. This subscale measured specific beliefs about the efficacy of treatment, the chances for future health and survival, as well as general feelings about the future (Cronbach’s α = 0.81).</p> | <ul style="list-style-type: none"> - The first outcome measure was participants’ level of psychological adjustment. This was assessed using: <ul style="list-style-type: none"> (iv) The Profile of Mood States (POMS). (v) The Global Adjustment to Illness Scale (GAIS). (vi) A single item from “The Quality Of Life Questionnaire” that had been designed for the study, which asked participants to rate the quality of their recent life on a 5-point Likert-type scale (from “very poor” to “excellent”). - The second outcome measure was physical health. This was assessed through: <ul style="list-style-type: none"> (iv) Nurse reports on a 7-point Likert-type scale using clinical impression and data from the patients’ medical charts. (v) The 5-item patient functioning subscale of “The Quality Of Life Questionnaire”, which tapped overall physical health and functional capabilities such as ability to engage in leisure/social activities. (vi) The number of days post-transplant until the first treated infection/rejection in addition to the overall number of such complications experienced. | <ul style="list-style-type: none"> - No significant differences were detected between participants with ‘high pre-transplant expectations’ and those with ‘low pre-transplant expectations’ who had suffered at least one complication within their first 6 months of post-transplant life on any of the post-transplant measures of psychological adjustment (ts = .18 - .87, ps>.40). - A partial multiple regression analysis was performed using the nurse’s ratings of post-transplant health as the dependent variable. Pre-transplant positive expectation scores were found to be a strong predictor of post-transplant health, explaining over 40% of the unique variance in post-transplant health as rated by the transplant nurse, after covarying for adherence and pre-transplant health (change in R^2=.35, adjusted R^2=.46), $F(3, 27)$=7.73, p<.01. - Pre-transplant positive expectation scores were used to predict medical complications with the first 6 months post-transplant. Twenty-four patients experienced at least one complication during this period. No relationship was found between high pre-transplant expectations and either: (i) the number infections/rejections experienced post-transplant; or (ii) the latency until first rejection experienced post-transplant. However, there was a tendency toward a significant relationship between pre-transplant expectation scores and latency until first post-transplant infection (r=.28, p<.15). |

| | | | | | |
|--|---|--|---|--|--|
| <p>Lee et al. (2003)</p> <p>– Good Quality</p> <p>[conducted in the USA]</p> | <p>313 adult hematopoietic stem cell transplant patients</p> <p><u>characteristics</u></p> <ul style="list-style-type: none"> - 164 males; 149 females - median age=47yrs (range=19-66yrs) - 296 caucasian; 17 noncaucasian - 95 early disease stage; 190 intermediate disease stage; 28 advanced disease stage <p><u>inclusion/exclusion criterion:</u></p> <ul style="list-style-type: none"> - must be an adult patient - must be able to read English | <ul style="list-style-type: none"> - This study employed a prospective longitudinal design. - Questionnaire data was collected from participants before they received their transplantation and at 6 months post-transplant. | <ul style="list-style-type: none"> - Pre-transplant expectations were classified according to participants' level of agreement with 2 statements "I am optimistic that my transplant will go well" and "If anything can go wrong with my transplant, it will". Participants responded using a 5 point Likert Scale with answer options ranging from "strongly disagree" to "strongly agree". - Participants who endorsed strong agreement with the first statement and strong disagreement with the second statement were considered to have "high expectations" compared to all the other response combinations. | <ul style="list-style-type: none"> - The outcome measures employed were post-transplant survival, quality of life, and experience of "bothersome symptoms". - Post-transplant survival was ascertained through participants' post-transplant medical records. - Quality of life was assessed through patient responses on the 'The Medical Outcomes Study Short Form 36' (SF36) and 'The Spitzer Quality of Life Index' (QLI). - Patients' experience of "bothersome symptoms" (fatigue, anxiety, depression, pain, difficulty concentrating, skin changes, and financial problems) were evaluated through Likert scales developed by the research team. | <ul style="list-style-type: none"> - The study data were analysed through multivariate models, built using a forward stepwise approach. The results showed that participants with low pre-transplant expectations had a significantly higher risk of mortality across their first two months of post-transplant life, compared with patients who had held positive pre-transplant expectations, after controlling for disease stage, patient age, and the presence of acute graft-versus-host disease (16% vs 8%; RR 2.20, 95% confidence interval [CI] 1.08-4.46; P=.03). Nevertheless, the results showed that participants with high and low pre-transplant expectations had an equal risk of mortality after their first two months of post-transplant life. - Univariate comparisons showed there were no significant differences between participants who had experienced high versus low pre-transplant expectations in terms of their quality of life at 6 months post-transplant as measured through the SF36 and QLI, or in their experience of "bothersome symptoms". |
|--|---|--|---|--|--|

| | | | | | |
|--|--|--|--|---|--|
| <p>Andrykowski et al. (1995)</p> <p>– Moderate Quality</p> <p>[conducted in the USA]</p> | <p>172 disease-free adult bone marrow transplant survivors</p> <p><u>characteristics</u></p> <ul style="list-style-type: none"> - 106 males; 66 females - mean age=39.1yrs (range=19-70yrs) - ethnicity not reported - mean time since transplant=43.5months (range=12-124months) <p><u>inclusion/exclusion criterion:</u></p> <ul style="list-style-type: none"> - must be able to read, write and understand English - must be at least 18yrs of age - must be a resident of the USA - must be at least 12months post-transplant - must be in disease remission | <ul style="list-style-type: none"> - Cross-sectional design. - When participants opted-in to the study they were interviewed over the telephone and mailed data collection questionnaires to complete. | <p>Pre-transplant expectations were operationalised through a single open-ended interview question devised by the research team: “Prior to your transplant, did you expect that you would have returned to normal by this time?”</p> | <ul style="list-style-type: none"> - Post-transplant normalcy was measured through a single open-ended interview question devised by the research team: “Do you consider yourself to have returned to normal following your transplant?”. - Post-transplant psychological distress was measured through four self-rated questionnaires: <ul style="list-style-type: none"> (i) Profile of Mood States (POMS) (ii) Psychological Adjustment to Illness Scale (PAIS) (iii) Rosenberg Self-Esteem Scale (RSE) (iv) Positive and Negative Affect Scale (PANAS) | <ul style="list-style-type: none"> - Post-transplant levels of psychological distress were unrelated to whether participants viewed themselves as having returned to normal when they had not expected this to happen pre-transplant. - Pre-transplant expectations that one would ‘return to normal’ following transplantation were associated with higher levels of psychological distress in patients who perceived themselves as having not returned to normal post-transplant (than in those who did feel they had returned to normal). |
|--|--|--|--|---|--|

| | | | | | |
|--|---|--|--|---|--|
| <p>Holzner et al. (2001)</p> <p>– Moderate Quality</p> <p>[conducted in Austria]</p> | <p>55 adult patients who had received a liver transplant</p> <p><u>characteristics</u></p> <ul style="list-style-type: none"> - 32 males; 23 females - average age=51.9yrs (s.d=11.9yrs) - ethnicity not reported - average time since transplant=4.7yrs(s.d.=3.2yrs) <p><u>inclusion/exclusion criterion:</u></p> <ul style="list-style-type: none"> - must be at least 18yrs of age - must be at least 12months post-transplant - must have no other severe illness at the time of the study | <ul style="list-style-type: none"> - A cross-sectional design was employed. - All data were collected post-transplant. - Participation comprised of a telephone interview (always conducted by the same interviewer) and the self-completion of study questionnaires. | <p>Pre-transplant expectations were assessed through a single interview question: "Before transplantation, did you expect your life would normalise after the surgery?". Response categories were: "positive expectations", "negative expectations", and "no expectations at all".</p> | <ul style="list-style-type: none"> - The outcome measures were self-perceived normalcy and quality of life post-transplant. - Normalcy was assessed through a single interview question "Would you say that through transplantation your life has normalised again?". Response categories were: "yes"; "with some limitations"; and "no". - Quality of life was self-rated through two standardised questionnaires: <ul style="list-style-type: none"> (i) The Sickness Impact Profile (SIP) (ii) The Functional Assessment of Cancer Therapy – General (FACT-G). | <ul style="list-style-type: none"> - A significant interaction effect was found between 'pre-transplant expectations' and 'post-transplant normalcy' on participants' FACT-G scores ($F_{1,46} = 5.11, p = 0.029$). - When participants <i>did not</i> view themselves as being back to normal post-transplant, those whose pre-transplant expectations were unfulfilled reported having a significantly lower quality of life (as measured by the FACT-G) than those who had never expected their lives would return to normal post-transplant (Mann-Whitney U test, $p < 0.023$). - No relationship was found between pre-transplant expectations and post-transplant quality of life (as measured by the FACT-G) in the group of participants who <i>did</i> view themselves as being back to normal post-transplant. - There was no interaction effect between patients' pre-transplant expectations and their post-transplant normalcy on the participants' SIP scores. |
| <p>Pommer et al. (1985)</p> <p>– Poor Quality</p> <p>[conducted in Germany]</p> | <p>33 adult kidney transplant patients</p> <p><u>characteristics</u></p> <ul style="list-style-type: none"> - 21 males; 12 females - mean age=42.1yrs (range unclear) - ethnicity not reported <p><u>inclusion/exclusion criterion:</u></p> <ul style="list-style-type: none"> - no criterion reported | <ul style="list-style-type: none"> - This study utilised a prospective longitudinal design. - Data was gathered before kidney transplantation and three months after the procedure. | <p>Pre-transplant expectations were measured through an 8-item self-report questionnaire developed by the research team.</p> | <p>The outcome measure used was whether participants' donor kidneys were still "healthy" at 3 months post-transplant (dichotomised as "successful" or "unsuccessful" transplants).</p> | <p>In total, 40% of participants' were categorised as having unsuccessful transplants 3 months after the procedure. It was reported that this subsample had "distinctly lower scores of predicted transplant success" than the 60% of participants whose transplants <i>were</i> successful after 3 months.</p> |

APPENDIX 6: West of Scotland Research Ethics Committee Approval Letters

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
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Date 5th April 2013
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss Watson

| | |
|-------------------------|---|
| Study title: | Young People's Experiences and Expectations of Renal Transplants |
| REC reference: | 13/WS/0077 |
| Protocol number: | GN12KH566 (R&D number) |
| IRAS project ID: | 124999 |

The Research Ethics Committee reviewed the above application at the meeting held on 28 March 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Liz Jamieson, Liz.Jamieson@ggc.scot.nhs.uk.

Discussion

1) The Committee asked you to explain how capacity would be assessed. You advised that you would meet with the young person or the child and parent if under the age of 12 years and assess capacity. You also advised that you worked with young people and had experience of assessing capacity. The Committee asked if the Specialist Nurse would have a role. You advised that the Specialist Nurse would make the approach, explain what the study was about and ask if they would like to take part.

2) The Committee asked if there was a particular reason why 11 year olds had been included as 12 to 17 year olds would be easier to manage in terms of consent. You advised that you had no particular reason for including this range only that 11 year olds were within the

developmental range. The Committee suggested that it may be better to exclude this age group.

3) The Committee commented that this could be a sensitive subject and asked what support mechanisms were in place if a participant became distressed. You explained that the young people would be 6 months post transplant, they were regularly seen at Yorkhill Hospital and it was more than likely that these conversations had taken place before. Also the Psychologist working with the Renal Team had already agreed to pick up any issues that may arise as a result of the research.

4) The Committee asked why unsuccessful transplants had been excluded. You commented that this was a new area of research and the first step was to look at successful transplant.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Additional Conditions Specified by the REC

1) The Committee agreed that it would be helpful if '**Successful**' was added to the title of the research. The study documentation should be revised accordingly.

2) The Committee suggested that perhaps excluding 11 year olds would make consent easier. This is only a suggestion.

3) If any recording is taking place then this should be in the Information Sheets and Consent Forms saying that any quotes used will be anonymised.

4) In the Participant Information Sheets for both the young people aged 12 years + and parents and carers 'No' should be added at 'Do I have to take part?'

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved at the meeting were:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|--|----------------|---------------|
| GP/Consultant Information Sheets | 1 | 08 March 2013 |
| Interview Schedules/Topic Guides | 1 | 08 March 2013 |
| Investigator CV | 1 | 08 March 2013 |
| Other: Opt-in form(participants aged 12-16 years) | 1 | 08 March 2013 |
| Other: Opt-in form (Parent & Carer) | 1 | 08 March 2013 |
| Other: Opt-in form(participants aged 17 years) | 1 | 08 March 2013 |
| Other: Useful sources of help form(12years & older) | 1 | 08 March 2013 |
| Other: Useful sources of help form(11years) | 1 | 08 March 2013 |
| Other: Useful sources of help(parents & carers) | 1 | 08 March 2013 |
| Other: Academic supervisor CV - Dr S O'Connor | 1 | 08 March 2013 |
| Other: Academic supervisor CV - Dr J Pownall | 1 | 08 March 2013 |
| Participant Consent Form: Participants 17 years old | 1 | 08 March 2013 |
| Participant Consent Form: Assent form for participants 11 years old | 1 | 08 March 2013 |
| Participant Consent Form: Participants aged 12-16years | 1 | 08 March 2013 |
| Participant Consent Form: Parent & Carer(for participants aged 11 years) | 1 | 08 March 2013 |
| Participant Information Sheet: For parents and carers | 1 | 08 March 2013 |
| Participant Information Sheet: For young people aged 12 years + | 1 | 08 March 2013 |
| Participant Information Sheet: Who are 11 years old | 1 | 08 March 2013 |
| Protocol | 9 | 08 March 2013 |
| REC application | | 12 March 2013 |

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

| |
|-------------------|
| 13/WS/0077 |
|-------------------|

| |
|---|
| Please quote this number on all correspondence |
|---|

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Liz Jamieson
Committee Co-ordinator
On behalf of Dr Adam Burnel, Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: Joanne McGarry, NHS Greater Glasgow and Clyde Research & Development Service

West of Scotland REC 3

Attendance at Committee meeting on 28 March 2013

Committee Members:

| <i>Name</i> | <i>Profession</i> | <i>Present</i> | <i>Notes</i> |
|-------------------------|---|----------------|--------------|
| Dr Adam Burnel | Consultant Psychiatrist - Chair | Yes | |
| Mrs Bernadette Campbell | Non-Medical Prescribing Advisor | Yes | |
| Ms Suzanne Clark | Retired - Lay Plus Member | No | |
| Mrs Monica Ann Dickson | Retired - Lay Plus Member | Yes | |
| Dr Mark Fawcett | General Practitioner | Yes | |
| Ms Susan Fleming | Public Health Researcher | Yes | |
| Dr Anja Guttinger | Consultant in Sexual & Reproductive Health | No | |
| Mrs Mary Keenaghan | Clinical Auditor - Lay Member | No | |
| Mr Eoin MacGillivray | Retired Dentist - Vice Chair | No | |
| Dr Paul Mattison | Consultant Physician in Rehabilitation Medicine | Yes | |
| Dr Angus McFadyen | Reader in Health Statistics | Yes | |
| Dr Stuart Milligan | Lecturer in Palliative and Cancer Care | No | |
| Dr Stephen Noble | Consultant Anaesthetist | Yes | |
| Mrs Gillian Notman | Joint Occupational Therapy Lead Advisor | Yes | |
| Mrs Helen Ross | Lay Plus Member | Yes | |
| Mrs Rosie Rutherford | Lay Member | Yes | |

Also in attendance:

| <i>Name</i> | <i>Position (or reason for attending)</i> |
|------------------|---|
| Dr Judith Godden | Scientific Officer/Manager |
| Mrs Liz Jamieson | Committee Co-ordinator |

West of Scotland REC 3
 Ground Floor – The Tennent Institute
 Western Infirmary
 38 Church Street
 Glasgow
 G11 6NT

Miss Evelyn Watson
 Trainee Clinical Psychologist
 NHS Education for Scotland / NHS Ayrshire
 and Arran
 Doctorate in Clinical Psychology Training
 Programme
 Gartnavel Royal Hospital, Admin Building,
 1055 Great Western Road,
 Glasgow
 G12 0XH

Date 17 April 2013

 Direct line 0141 211 6294
 Fax 0141 211 1847
 E-mail Stephanie.keane@ggc.scot.nhs.uk

Dear Miss Watson

Study title: Young People's Experiences and Expectations of Renal
 Transplants
REC reference: 13/WS/0077
Protocol number: GN12KH566 (R&D number)
IRAS project ID: 124999

Thank you for your letter of 10 April 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 05 April 2013

Documents received

The documents received were as follows:

| Document | Version | Date |
|---|---------|---------------|
| Other: Opt-in form(12 - 16 years) | 2 | 09 April 2013 |
| Other: Opt-in form(17 years) | 2 | 09 April 2013 |
| Other: Opt-in form(parent_carer) | 2 | 09 April 2013 |
| Other: Uses sources of help(11years) | 2 | 09 April 2013 |
| Other: Uses sources of help(12years+) | 2 | 09 April 2013 |
| Other: Useful sources of help(parents_carers) | 2 | 09 April 2013 |

| | | |
|--|----|---------------|
| Participant Consent Form: Assent form | 2 | 09 April 2013 |
| Participant Consent Form: 12 - 16years | 2 | 09 April 2013 |
| Participant Consent Form: 17 years old | 2 | 09 April 2013 |
| Participant Consent Form: Parent consent form(participants 11 years old) | 2 | 09 April 2013 |
| Participant Information Sheet: Info form 11 years | 2 | 09 April 2013 |
| Participant Information Sheet: Info form 12years + | 2 | 09 April 2013 |
| Participant Information Sheet: Info form_parent_carer | 2 | 09 April 2013 |
| Protocol | 10 | 09 April 2013 |

Approved documents

The final list of approved documentation for the study is therefore as follows:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|--|----------------|---------------|
| GP/Consultant Information Sheets | 1 | 08 March 2013 |
| Interview Schedules/Topic Guides | 1 | 08 March 2013 |
| Investigator CV | 1 | 08 March 2013 |
| Other: Academic supervisor CV - Dr S O'Connor | 1 | 08 March 2013 |
| Other: Academic supervisor CV - Dr J Pownall | 1 | 08 March 2013 |
| Other: Opt-in form(12 - 16 years) | 2 | 09 April 2013 |
| Other: Opt-in form(17 years) | 2 | 09 April 2013 |
| Other: Opt-in form(parent_carer) | 2 | 09 April 2013 |
| Other: Uses sources of help(11years) | 2 | 09 April 2013 |
| Other: Uses sources of help(12years+) | 2 | 09 April 2013 |
| Other: Useful sources of help(parents_carers) | 2 | 09 April 2013 |
| Participant Consent Form: Assent form | 2 | 09 April 2013 |
| Participant Consent Form: 12 - 16years | 2 | 09 April 2013 |
| Participant Consent Form: 17 years old | 2 | 09 April 2013 |
| Participant Consent Form: Parent consent form(participants 11 years old) | 2 | 09 April 2013 |
| Participant Information Sheet: Info form 11 years | 2 | 09 April 2013 |
| Participant Information Sheet: Info form 12years + | 2 | 09 April 2013 |
| Participant Information Sheet: Info form_parent_carer | 2 | 09 April 2013 |
| Protocol | 10 | 09 April 2013 |
| REC application | | 12 March 2013 |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

| | |
|-------------------|---|
| 13/WS/0077 | Please quote this number on all correspondence |
|-------------------|---|

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. Keane'.

Stephani Keane
Admin Assistant

Copy to: Joanne McGarry, NHS Greater Glasgow and Clyde Research & Development Service

APPENDIX 7: Greater Glasgow and Clyde Research and Development Approval Letter

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor, 38 Church Street
Glasgow, G11 6NT



Coordinator/Administrator: JMcG/ LR
Direct Line: 0141 211 8548
E-mail: Joanne.McGarry@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

24th May 2013

Miss Evelyn Watson
Trainee Clinical Psychologist
Doctorate in Clinical Psychology Training Programme
Gartnavel Royal Hospital
Admin Building
1055 Gt Western Road
G12 0XH

NHS GG&C Board Approval

Dear Miss Watson

Study Title: Young People's Experiences and Expectations of Renal Transplant
Chief Investigator: Miss Evelyn Watson
GG&C HB site: RHSC
Sponsor: NHS GG&C Health Board
R&D Reference: GN12KH566
REC Ref: 13/WS/0077
Protocol no: V10 dated 09/04/13

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information related solely to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. Recruitment Numbers on a monthly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures

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NonCommApproval_R&D_041010_V3

e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely



Joanne McGarry
Research Co-ordinator

CC: Dr J Pownall, Academic Supervisor, Glasgow
Dr S O'Connor, Academic Supervisor, Glasgow
Dr D Hughes, RHSC, Glasgow

APPENDIX 8: Participant Information Forms



University
of Glasgow



Information Sheet for Young People (who are 11 years old)

Young People's Experiences and Expectations of Successful Renal Transplants

A research study

Please read this information sheet.

You can ask a parent or carer to help you.



What is this about?

This is a study aimed at learning what it is like to have a kidney transplant when you are a young person.

Why have I been asked to take part?

We are asking you to take part because we would like to know about your experience of having a kidney transplant.

Do I have to take part?

No. You and your parent or carer decide if you want to take part. It is also ok if you change your mind at any point. It is your choice.

How do I let you know if I want to take part?

You can let your parent or carer know and they can tell me.

What will happen if I want to take part?

We will meet with you and your parent or carer.



We will ask you to sign a form to say you are happy to take part.

We will meet with you for about 1 hour.



In the meeting, we will ask you some questions about what it was like to have a kidney transplant. You do not have to answer any questions if you don't want to.

Your parent or carer will also fill out some forms for us.

What if I change my mind and do not want to take part?

You can change your mind or stop at any time. Nobody will be upset and you don't have to say why.

Will other people find out about what I say?

What you say will be confidential. The things you tell me will not have your name on, so no one will know that you've said them.

The only time we might have to talk to somebody else about what you have said is if we think you might need some extra help. This will only happen if we are worried about you or somebody else.

We will send a letter to your GP to let them know that you took part in the study but this letter won't mention the things you say during the interview with the researcher.

What happens to what I say?

We will be meeting with lots of young people who have had a kidney transplant and asking them what this was like.

After this, we will gather together all of the information young people give us. We will then use this information to write a report that explains what it is like to have a kidney transplant when you are a young person. The things you tell me will not have your name on, so no one will know that you've said them.

The report we write will help other people understand what it is like to have a kidney transplant. The information collected during the study may be helpful in preparing other young people for kidney transplants.

Will I be able to find out the results of the study?

Yes. Once the study has finished, we will give you and your parent or carer information about it.

What if I have any questions about the study?

If you have any questions regarding the study at any time you can write to us or phone us.

**Dr. Suzy O'Connor (Clinical Tutor) / Dr. Jaycee Pownall (Research Associate) /
Evelyn Watson (Trainee Clinical Psychologist)**

**University of Glasgow Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
1055 Great Western Road
Glasgow
G12 0XH**

Dr. Janie Donnan (Principal Clinical Psychologist)

**Department of Paediatric Psychology
Yorkhill Royal Hospital for Sick Children
Dalnair Street
Glasgow
G3 8SJ**

Thank you for reading this.

Young People's Experiences and Expectations of Successful Renal Transplantation

Information Sheet (for young people aged 12 years +)

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

The research is being carried out by:

- Dr. Janie Donnan (Principal Clinical Psychologist, Department of Paediatric Psychology at Yorkhill Royal Hospital for Sick Children)
- Dr. Suzy O'Connor (Clinical Tutor on the University of Glasgow Doctorate in Clinical Psychology Training Programme)
- Dr. Jaycee Pownall (Research Associate on the University of Glasgow Doctorate in Clinical Psychology Training Programme)
- Evelyn Watson (Trainee Clinical Psychologist on the University of Glasgow Doctorate in Clinical Psychology Training Programme)

What is the purpose of the study?

This is an academic research study that aims to advance our understanding of what it is like for young people to have a kidney transplant (from the point of forming pre-transplant expectations).

Why have I been invited?

You have been invited to take part in this study because we would like to learn about your experience of having a kidney transplant.

Do I have to take part?

No. It is up to you to decide whether you would like to take part. You are also free to withdraw from the study at any time, without giving reason. If you decide not to take part, or withdraw from the study at a later date, this would not affect the standard of care you receive or your future treatment.

What does taking part involve?

If you would like to take part one member of the researcher team will meet with you at the hospital that you normally attend for your follow-up clinic appointments with the renal transplant team.

When we meet you we will describe the study, go through this information sheet and answer any questions that you have about the study. You will then be asked to sign a consent form to show you have agreed to take part. If you are 12-16 years old then we will also ask for parental consent for you to take part.

We will then ask you some questions about what it is like to have a kidney transplant. You do not have to answer any questions that you do not want to.

What happens to the information?

Your identity and personal information will be completely confidential and known only to the research team. The interviews will be recorded and transcribed. Any quotes used in the final study report will be anonymised. All recordings will be destroyed immediately following transcription. All information obtained will remain confidential and be stored on secure University of Glasgow computer drives that can only be accessed by the research team. The data are held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission.

General Practitioners

If you participate in the study we will send a letter to your general practitioner (GP) to let them know that you have taken part.

What are the possible benefits of taking part?

It is hoped that by taking part in this research, you will be providing valuable information about what it is like for young people to have a kidney transplant. This could help other people to understand the experience better, including health professionals. The information may also be useful in helping other young people to prepare for kidney transplants in the future.

Who has reviewed the study?

This study has been reviewed by the 'University of Glasgow Doctorate in Clinical Psychology Training Programme', the 'NHS West of Scotland Research Ethics Service' and the 'NHS Greater Glasgow and Clyde Research & Development Service'.

If you have any further questions?

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study, please contact:

Dr. Janie Donnan (principal clinical psychologist)
Department of Paediatric Psychology
Yorkhill Royal Hospital for Sick Children
Dalnair Street
Glasgow
G3 8SJ

Dr. Suzy O'Connor (Clinical Tutor) / Dr. Jaycee Pownall (Research Associate) /
Evelyn Watson (Trainee Clinical Psychologist)

University of Glasgow Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
1055 Great Western Road
Glasgow
G12 0XH

If you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the research team in the first instance but the normal NHS complaint mechanisms is also available to you.

Thank-you for your time and co-operation.

University of Glasgow Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
1055 Great Western Road
Glasgow
G12 0XH

Young People's Experiences and Expectations of Successful Renal Transplants

Information Sheet (for parents and carers)

We would like to invite your child to take part in a research study. Before you decide whether to give your consent for them to participate you need to understand why the research is being done and what it would involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

The research is being carried out by:

- Dr. Janie Donnan (Principal Clinical Psychologist, Department of Paediatric Psychology at Yorkhill Royal Hospital for Sick Children)
- Dr. Suzy O'Connor (Clinical Tutor on the University of Glasgow Doctorate in Clinical Psychology Training Programme)
- Dr. Jaycee Pownall (Research Associate on the University of Glasgow Doctorate in Clinical Psychology Training Programme)
- Evelyn Watson (Trainee Clinical Psychologist on the University of Glasgow Doctorate in Clinical Psychology Training Programme)

What is the purpose of the study?

This is an academic research study that aims to advance our understanding of what it is like for young people to have a kidney transplant (from the point of forming their pre-transplant expectations).

Why is my child being invited to take part?

We are inviting them to take part in this study because we would like to learn about their experience of having a kidney transplant.

Do they have to take part?

No. It is up to you to decide whether you would like your child to take part. You are also free to withdraw parental consent at any time, without giving reason. If you decide that you do not want them to take part, or withdraw parental consent at a later date, this would not affect the standard of care they receive or their future treatment.

What does taking part involve?

If you give parental consent for your child to take part then one member of the researcher team will meet with you and your child at the hospital that they normally attend for their follow-up clinic appointments with the renal transplant team.

When the researcher meets your family they will describe the study, go through this information sheet and answer any questions that you have about the study. You will then be asked to sign a parental consent form to

show you have agreed for your child to take part. We will also ask your child to sign a consent form to show that they wish to take part.

We will then ask your child some questions about what it is like to have a kidney transplant. They do not have to answer any questions that they do not want to.

What happens to the information?

Your child's identity and personal information will be completely confidential and known only to the research team. The interviews will be recorded and transcribed. All recordings will be destroyed immediately following transcription. Any quotes used in the final study report will be anonymised. All information obtained will remain confidential and be stored on secure University of Glasgow computer drives that can only be accessed by the research team. The data are held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission.

General Practitioners

If your child participates in the study we will send a letter to their general practitioner (GP) to let them know that they have taken part.

What are the possible benefits of taking part?

It is hoped that by taking part in this research, your child will be providing valuable information about what it is like for young people to have a kidney transplant. This could help other people to understand the experience better, including health professionals. The information may also be useful in helping other young people to prepare for kidney transplants in the future.

Who has reviewed the study?

This study has been reviewed by the 'University of Glasgow Doctorate in Clinical Psychology Training Programme', the 'NHS West of Scotland Research Ethics Service' and the 'NHS Greater Glasgow and Clyde Research & Development Service'.

If you have any further questions?

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study please contact:

| |
|---|
| Dr. Janie Donnan (principal clinical psychologist) Department of Paediatric Psychology Yorkhill Royal Hospital for Sick Children Dalnair Street Glasgow G3 8SJ |
|---|

| |
|--|
| Dr. Suzy O'Connor (Clinical Tutor) / Dr. Jaycee Pownall (Research Associate) / Evelyn Watson (Trainee Clinical Psychologist) University of Glasgow Doctorate in Clinical Psychology Programme Gartnavel Royal Hospital Admin Building 1055 Great Western Road Glasgow G12 0XH |
|--|

If you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the research team in the first instance but the normal NHS complaint mechanisms is also available to you.

Thank-you for your time and co-operation.

APPENDIX 9: Participant Opt-In Forms

Department of Paediatric Psychology
Yorkhill Royal Hospital for Sick Children
Dalnair Street
Glasgow
G3 8SJ

Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
1055 Great Western Road
Glasgow
G12 0XH



University
of Glasgow



Subject Number:

Young People's Experiences and Expectations of Successful Renal Transplants

Parent and Carer Opt-In Form (for participants aged 11 years old)

Please Initial Box

I confirm that I have read the parent information sheet dated 09/04/2013
(Version 2) for the above study.

☐

I understand that my child's participation is voluntary and that I am free
to withdraw them from the study at any time, without giving any reason,
without my child's medical care or legal rights being affected.

☐

I would like to opt-in my child to the above study.

☐

I agree for the research team to contact me by telephone to arrange an
interview with my child.

☐

Name of Parent

Date

Signature

Name of Person Taking Consent

Date

Signature

I copy to the patient, 1 copy to the researcher, 1 original for the patient's notes

Department of Paediatric Psychology
Yorkhill Royal Hospital for Sick Children
Dalnair Street
Glasgow
G3 8SJ



University
of Glasgow



Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
1055 Great Western Road
Glasgow
G12 0XH

Subject Number:

Young People's Experiences and Expectations of Successful Renal Transplants

Young Person's Opt-In Form (for those aged 12-16 years old)

Please Initial Box

I confirm that I have read the information sheet dated 09/04/2013 (Version 2) for the above study.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐☐

I would like to opt-in to the above study.

I agree for the research team to contact me by telephone to arrange an interview with them.

☐

Name

Date

Signature

Name of Parent or Carer

Date

Signature

Name of Person Taking Consent

Date

Signature

1 copy to the patient, 1 copy to the researcher, 1 original for the patient's notes

Department of Paediatric Psychology
Yorkhill Royal Hospital for Sick Children
Dalnair Street
Glasgow
G3 8SJ



Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
1055 Great Western Road
Glasgow
G12 0XH

Subject Number:

Young People's Experiences and Expectations of Successful Renal Transplants

Young Person's Opt-In Form (for those aged 17 years old)

Please Initial Box

I confirm that I have read the information sheet dated 09/04/2013 (Version 2) for the above study.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I would like to opt-in to the above study.

☐

I agree for the research team to contact me by telephone to arrange an interview with them.

☐

Name

Date

Signature

Name of Person Taking Consent

Date

Signature

1 copy to the patient, 1 copy to the researcher, 1 original for the patient's notes

APPENDIX 10: Participant Consent Forms

Department of Paediatric Psychology
Yorkhill Royal Hospital for Sick Children
Dalnair Street
Glasgow
G3 8SJ

Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
1055 Great Western Road
Glasgow
G12 0XH



University
of Glasgow



Subject Number:

ASSENT FORM FOR CHILDREN

(To be completed by the child and their parent/guardian)

Project Title: Young People's Experiences and Expectations of Successful Renal Transplants

To be completed by the child (or if unable, the parent on their behalf).

Please circle your answers:

| | |
|--|--------|
| Have you read (or had read to you) information about this project? | Yes/No |
| Has somebody else explained this project to you? | Yes/No |
| Do you understand what this project is about? | Yes/No |
| Have you asked all the questions you want? | Yes/No |
| Have you had your questions answered in a way that you understand? | Yes/No |
| Do you understand that it's OK to stop taking part at any time? | Yes/No |
| Are you happy for the interview to be recorded? | Yes/No |
| Do you understand that the interview recording will be destroyed after it has been typed up? | Yes/No |
| Do you understand that any quotes used in the final study report will be anonymised? | Yes/No |
| Are you happy to take part? | Yes/No |

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to be phoned by the research team, you can sign your name below

Your name _____
Signature _____
Date _____

The clinician who explained this project to you needs to sign too:

Print Name _____
Signature _____
Date _____

Thank you for your help

1 copy to the patient, 1 copy to the researcher, 1 original for the patient's notes

Department of Paediatric Psychology
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of Glasgow



Doctorate in Clinical Psychology Programme
Gartnavel Royal Hospital
Admin Building
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Glasgow
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Subject Number:

Young People's Experiences and Expectations of Successful Renal Transplants

Parent and Carer Consent Form (for participants aged 11 years old)

Please Initial Box

I confirm that I have read the information sheet dated 09/04/2013 (Version 2) for the above study.

☐

I have had a chance to discuss this study and ask questions.

☐

I have received satisfactory answers to all of my questions.

☐

I have received enough information about the study.

☐

I agree to my child's interview being recorded.

☐

I understand that the interview recording will be destroyed following its transcription.

☐

I understand that any quotes used in the final study report will be anonymised.

☐

I understand that my child's participation is voluntary and that I am free to withdraw my consent at any time, without giving any reason, without my child's medical care or legal rights being affected.

☐

I understand that sections of my child's medical notes may be looked at by the research team where it is relevant to their participation in the research. I give my permission for the research team to have access to my child's records.

☐

I agree for my child to take part in the above study.

☐

Name of Parent

Date

Signature

Name of Person Taking Consent

Date

Signature

I copy to the patient, 1 copy to the researcher, 1 original for the patient's notes

Department of Paediatric Psychology
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of Glasgow



Subject Number:

Young People's Experiences and Expectations of Successful Renal Transplants

Young Person's Consent Form (for those aged 12-16 years old)

Please Initial Box

I confirm that I have read the information sheet dated 09/04/2013 (Version 2) for the above study.

☐

I have had a chance to discuss this study and ask questions.

☐

I have received satisfactory answers to all of my questions.

☐

I have received enough information about the study.

☐

I agree to my interview being recorded.

☐

I understand that the interview recording will be destroyed following its transcription.

☐

I understand that any quotes used in the final study report will be anonymised.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I understand that sections of my medical notes may be looked at by the research team where it is relevant to my taking part in the research. I give my permission for the research team to have access to my records.

☐

I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Name of Parent or Carer

Date

Signature

Name of Person Taking Consent

Date

Signature

1 copy to the patient, 1 copy to the researcher, 1 original for the patient's notes

Department of Paediatric Psychology
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1055 Great Western Road
Glasgow
G12 0XH

Subject Number:

Young People's Experiences and Expectations of Successful Renal Transplants

Young Person's Consent Form (for those aged 17 years old)

Please Initial Box

I confirm that I have read the information sheet dated 09/04/2013 (Version 2) for the above study.

☐

I have had a chance to discuss this study and ask questions.

☐

I have received satisfactory answers to all of my questions.

☐

I have received enough information about the study.

☐

I agree to my interview being recorded.

☐

I understand that the interview recording will be destroyed following its transcription.

☐

I understand that any quotes used in the final study report will be anonymised.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I understand that sections of my medical notes may be looked at by the research team where it is relevant to my taking part in the research. I give my permission for the research team to have access to my records.

☐

I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Name of Person Taking Consent

Date

Signature

1 copy to the patient, 1 copy to the researcher, 1 original for the patient's notes

APPENDIX 11: Semi-Structured Interview Schedule

Interview Questions and Prompts

1. Can you tell me a little bit about yourself?

- Prompts*
- how old are you?
 - who are the important people in your life?
 - do you go to school?
 - do you work?
 - what do you like to do in your spare time?
 - how old were you when you had your transplant?

2. Can you tell me a little bit about what it was like to have a transplant?

- Prompts*
- how did you prepare for your transplant?
 - was there anything you didn't understand?
 - can you think of anything that would have helped you prepare better?
 - what was it like being in hospital?
 - were there things about having a transplant that worried you (before you had your transplant)?
 - were there things about having a transplant that you were looking forward to (before you had your transplant)?

3. How has your life changed since you had your transplant?

- Prompts*
- what was it like when you went home at first?
 - did you have any thoughts about what might change after your transplant?
 - what things have been easier since you had your transplant?
 - what things have been more difficult since you had your transplant?
 - was there anything more difficult than you thought it would be?
 - was there anything that would have helped you prepare better?
 - is there anything that is easier than you thought it would be?
 - is there anything you would have liked to know more about before you had your transplant?

4. What is it like to have a new kidney?

- Prompts*
- do you spend much time thinking about your new kidney?
 - can you tell me a little bit about the kind of thoughts you have?
 - are there any good things about having a new kidney?
 - are there any bad things about having a new kidney?
 - has the transplant changed the way you feel about yourself?
 - did other people treat you differently after your transplant?
 - how does having a transplant compare to being on dialysis?

5. Does having had a kidney transplant make a difference to how you look after your health?

- Prompts*
- what did you have to do before to look after yourself?
 - how has this changed?
 - what do you think about that?
 - what do you have to do to look after your new kidney?
 - what is that like?

6. Has the transplant affected your family relationships?

- Prompts*
- does your mum/dad/(other main carer)/brother(s)/sister(s) treat you differently now (after having your transplant)?
 - what do you think about that?
 - did you expect them to treat you differently?
 - do you think they understand what it is like to have a transplant?
 - has the transplant changed the way you think about your family?

7. Has the transplant affected your friendships?

- Prompts*
- did you feel different from your friends before your transplant?
 - do you feel different from your friends now?
 - did your friends treat you differently after you had your transplant?
 - what do you think about that?
 - were you expecting them to treat you differently?
 - do you talk to your friends about your transplant?
 - do your friends understand what it is like to have a transplant?
 - what do your friends think about you having had a transplant?
 - has the transplant changed what you do with your friends?

8. Has the transplant affected any other areas of your life?

- Prompts*
- has it changed how you get on at school/work?
 - has it changed how you spend your free time?

9. Do you feel that having a transplant was the right option for you?

10. Do you think you were the right age when you had your transplant?

11. What would you tell other young people to expect before they had a kidney transplant?

- Prompts*
- can you think of anything that might help other young people prepare for their transplant?

12. Is there anything else that you think is important that we haven't talked about?

13. Do you have any questions that you would like to ask me?

APPENDIX 12: Major Research Project Proposal

TITLE

Young People's Experiences and Expectations of Successful Renal Transplants

ABSTRACT

Background

Kidney transplantation is currently the treatment of choice for young people with life-threatening kidney failure but it is not a curative treatment and secondary medical problems can occur following transplant surgery. After receiving a kidney transplant young people must adhere to a strict medication regimen to prevent their body from rejecting their transplanted kidney. Those who are between 11-17 years of age are at high risk of losing their transplanted kidney and this vulnerability has been partly attributed to medication non-adherence. Young people are also vulnerable to the development of psychological and social difficulties after their kidney transplant operations. Medication non-adherence may be more likely in young people because the prefrontal areas of the brain are not fully developed during adolescence. The prefrontal areas of the brain are responsible for higher order cognitive functions such as risk assessment, problem solving, and impulse control which are necessary for making 'good judgments' and foreseeing the future consequences of current actions. This means that young people are more likely to overlook the long-term dangers of not taking their medication and to engage in this behaviour. Until this stage of neurodevelopment is achieved young people are also likely to suffer from the personal fable that bad things only happen to others which would make it more likely that they would envision only positive outcomes after their kidney transplants. This would leave them unprepared for the possibility of negative outcomes. Unfulfilled pre-transplant expectations could be experienced as a loss and leave young people vulnerable to psychological difficulties.

Aims

The principal aims of this study are to build a detailed understanding of young people's lived experience through the kidney transplant process, from the point of forming their pre-transplant expectations, and to learn more about the meaning they construct around this experience.

Methods

Semi-structured interviews will be conducted with ten young people who have had a kidney transplant exploring their pre-transplant expectations, their experience of what the kidney transplant process was like, their experience of how their lives have been affected by having had a kidney transplant, and their perspectives on whether their pre-transplant expectations were fulfilled by their kidney transplant operations. All interviews will be recorded and transcribed, then analysed using thematic analysis to identify key themes.

Application

This study will lead to a deeper understanding of young people's lived experiences across the kidney transplant process from the point of forming pre-transplant expectations. This knowledge could be used to identify those who are at risk of developing psychological difficulties at an early stage in the transplant process in order to provide them with information about what to expect, and to better prepare them for their transplant operations. This could positively impact on medication adherence after transplant and reduce the risk of mental health problems developing.

INTRODUCTION

End stage renal disease is a life-threatening medical condition which represents the last phase of chronic kidney failure. The kidney functioning of people with end stage renal disease is under 15% (Ratcliff et al., 2010). Kidney transplantation is currently the treatment of choice for young people with end stage renal disease (NICE, 2006; Diseth et al., 2011). Through the delivery of a functioning donor kidney, the procedure aims to prolong life, increase physical health, and enhance quality of life (Manificat et al., 2003). Following kidney transplantation people must adhere to a strict immunosuppressant medication regimen to prevent their body from rejecting the donated organ (Ratcliff et al., 2010). Post-transplant, people are at risk of developing secondary medical problems such as reduced bone mass, infection, anaemia, and loss of functioning in their transplanted kidney (Berber et al., 2006; Sokal, 1995). Kidney transplantation is not a curative treatment (Anthony et al., 2010) and recipients often require further interventions at a later date (e.g. haemodialysis, peritoneal dialysis, additional transplants) (Stein & Wild, 2010).

Young people aged between 11-17 years old have been identified as a patient population at high risk of losing their transplanted kidney (Magee et al., 2004). This vulnerability has been partly attributed to medication non-adherence (Dobbels et al., 2005). Research suggests that young people are also

vulnerable to developing a range of psychosocial adjustment difficulties following kidney transplantation including anxiety, depression, low self-esteem, relationship problems, body image concerns, poor academic achievement, and lifestyle restrictions (Garralda et al., 1988; Anthony et al., 2010; Dobbels et al., 2010). Adolescence is a stressful period of transition when several important developmental tasks must be undertaken such as building self-identity and achieving independence (Dobbels et al., 2005). Peer opinion is very important to young people (Steinberg, 2005) and those who have received a kidney transplant may be reluctant to take their medications if they do not want to feel different from their peers or if they view non-adherence as a way to distance themselves from an identity as a sick person (Ratcliff et al., 2010). Young kidney transplant recipients are likely to require significant support from the adults in their lives (Rianthavorn & Ettenger, 2005) and could feel indebted to any family member who had offered them a donated kidney (Fennell et al., 2001). This dependence and sense of being in debt to family members could limit opportunities to experiment and learn from normal adolescent peer experiences which would ordinarily lead to independence. It could also make it more difficult for young people to perceive themselves as individuals, separate from their family system.

Research suggests that the development of the prefrontal areas of the brain is not complete in adolescence (Davey et al., 2008). These areas are associated with higher order cognitive functions such as risk assessment, problem solving, and impulse control which are necessary for making 'good judgments' and foreseeing the future consequences of current behaviours (Choudhury, et al., 2006). Until this stage of neurodevelopment is achieved in the mid-twenties (Gogtay et al., 2004), young people are likely to believe that they are unique and invulnerable (Elkind, 1967; Choudhury et al., 2006). This makes it more likely that they will only expect positive outcomes after their kidney transplant and leave them unprepared for the possibility of negative outcomes. Limitations in the ability to recognise the long-term dangers of present actions will increase the likelihood that young people will engage in risky behaviours such as medication non-adherence which could endanger their transplanted kidney (Dobbels et al., 2010). Given that young people think differently from other age groups due to their developmental stage (neurological, cognitive, and social), it is important to learn more about their self-reported lived experience of having a kidney transplant from the point of them developing their pre-transplant expectations. This would permit a shared understanding of this experience to be developed that could be discussed with other young people who are considering a kidney transplant in order to help them make informed decisions and to ensure adequate preparation for treatment. Such early interventions could positively impact on

medication adherence after transplant and reduce the risk of mental health problems developing. Darbyshire et al. (2006) have argued that there is a strong need for more child-centred qualitative research given that previous investigations have often failed to gather young people's own views about their treatments and largely investigated post-transplant adjustment using an empirical framework that fails to capture the complexity of young people's experiences. Recent studies have found differences between the self-reported quality of life of young people who have received a kidney transplant and the estimates of their parents and physicians (Dobbels, et al., 2010; Ratcliff et al., 2010). This finding underlines the need to consult young people about their own experiences.

Before transplantation, young people with kidney failure are likely to have experienced a period of significant ill-health and to have considered how this might improve following their kidney transplant. It is possible that they may use their pre-transplant expectations (self-predicted outcomes) as a baseline for gauging later transplant success. Some young people may hold optimistic expectations (Stuber et al., 1996). Optimism has been identified as a factor which may operate to protect mental and physical wellbeing (Taylor et al., 2000). It has been argued that people who tend to approach their difficulties with optimistic expectations are more likely to employ goal-directed thinking when unwell and concentrate upon the steps necessary for recovery when experiencing ill-health (Snyder et al., 1997). Studies on young people who have different types of chronic illnesses have found that optimism is associated with greater treatment compliance, the application of more adaptive coping strategies, and lower levels of anxiety (Lewis and Kliewer, 1996; Kyngas et al., 2000).

Although it is recommended that expectations be one of the key elements considered during young people's pre-transplant psychosocial assessments (Annunziato et al., 2010), there is limited research focused upon this critical area. Olausson et al. (2006) completed a qualitative study on the experiences of paediatric patients who had received different types of transplanted organs. Although the majority of participants described their post-transplant lives as similar to that of healthy peers, some reported unfulfilled expectations which were related to negative psychosocial outcomes (e.g. an unmet expectation of support from others which induced feelings of rejection).

Despite the lack of paediatric research focused on this area, we can draw on studies that have explored the pre-transplant expectations of adult kidney transplant recipients. Findings suggest that although global quality of life is better following kidney transplantation, adult clients' pre-transplant expectations are significantly higher than their actual post-transplant outcomes (Smith et al., 2008).

It has been highlighted that patient adjustment may be negatively impacted when there is a considerable discrepancy between preoperative expectations and later results (Rose et al., 1995). This kind of experience could create a state of cognitive dissonance and feelings of loss. In a study on adult liver transplant recipients, Holzner et al. (2001) found that when clients' physical and psychosocial functioning was poor after transplant surgery, those who had previously held optimistic expectations viewed themselves as having a significantly lower quality of life than those who had originally reported a more sceptical outlook. Nevertheless, these results come from adult transplant populations and so it cannot be inferred, from such results, that similar effects operate in young people who have had a kidney transplant.

It is important to learn what young people expect their kidney transplant will offer them, whether their expectations are fulfilled post-transplant, what effect their unfulfilled expectations exert upon their psychosocial adjustment, and how unfulfilled expectations are worked through (particularly when young people must face later treatments such as a second transplant following the rejection of their first transplanted kidney). This understanding could be used to identify those at risk of developing psychosocial difficulties at an early stage in the transplant process in order to provide them with information about what to expect and to better prepare them for treatment. It could also be used to develop treatments for those who experience adjustment difficulties as a consequence of unfulfilled expectations.

The principal aims of this study are to build a detailed understanding of young people's lived experience through the kidney transplant process, from the point of forming their pre-transplant expectations, and to learn more about the meaning they construct around this experience.

AIMS

This study aims to advance our understanding of young people's lived experience through the kidney transplant process.

This study will explore young people's:

- (1) pre-transplant expectations about their kidney transplant
- (2) experiences of what the kidney transplant process was like
- (3) experiences of life following the kidney transplant
- (4) perspectives on whether their pre-transplant expectations were realised

METHODS

Participants

Consistent with Wells et al. (in press) we aim to employ a sample of ten participants. If theme saturation is not realised with ten participants, additional participants will be invited to participate consistent with Wells et al. (in press). At present approximately 40 young people who have been treated at Yorkhill Royal Hospital for Sick Children (Yorkhill RHSC), a local children's hospital, meet the study inclusion / exclusion criteria.

Study Inclusion Criteria

The study inclusion criteria are:

- (a) Participant must have had a successful healthy kidney transplant and be in active follow-up by the renal team at Yorkhill RHSC, consistent with Dobbels et al. (2010).
- (b) Time since transplant must be at least six months. This will allow a period of post-transplant adjustment, consistent with Anthony et al. (2010).
- (c) Time since transplant must be no more than five years as the study requires participants to recall life before their transplant, consistent with Holzner et al. (2001).
- (d) Participant must have the ability to speak English at a level that will permit them to provide a detailed account of their experiences, consistent with Smith et al. (2009).
- (e) Participant must be a young person aged 11-17 years, as this is the formal operational stage of development when young people may be expected to have the capacity for abstract thought (Piaget, 1936).

Study Exclusion Criteria

The study exclusion criteria are:

- (a) Participant has not had a successful kidney transplant, or has lost their donor kidney since having their transplant operation.
- (b) Participant is not in active follow-up by the renal team at Yorkhill RHSC.

- (c) Time since transplant has been less than six months.
- (d) Time since transplant has been more than five years.
- (e) Participant does not have the ability to speak English at a level that will permit them to provide a detailed account of their experiences.
- (f) Participant is younger than 11 years of age or is older than 17 years of age.

Procedure

The Yorkhill Royal Hospital for Sick Children (Yorkhill RHSC) renal nurse specialists will conduct a computerised search of their team's patient database to identify all potential participants who meet the study inclusion/exclusion criterion. During routine follow-up appointments the renal nurse specialists will explain that the study is taking part, gauge interest from potential participants, screen for ability to speak English, distribute information packs (containing study information forms and study opt-in forms), and collect completed opt-in forms. All potential participants will be approached by the renal nurse specialists at their next routine follow-up appointment once the recruitment stage begins. Recruitment will be purposive, consistent with Wells et al. (in press), and based on the order in which potential participants opt-in to the study. When potential participants sign their opt-in forms they will be contacted by the research team to arrange an interview at Yorkhill Royal Hospital for Sick Children (on a date most convenient for the participant, e.g. when they next attend for follow-up or another date of their choice).

Semi-structured interviews will be conducted with the ten recruited participants consistent with Braun and Clarke (2006). All interviews will be recorded and transcribed. The interviews will be conducted with the participating young people on their own, in the hospital where they normally attend for routine follow-up appointments with the renal transplant team (Yorkhill RHSC). It is expected that each interview will last approximately 1 hour with additional time added for comfort breaks as required. It is predicted that each interview will take 3-5 hours to transcribe. Psychosocial support will be available through the Yorkhill RHSC renal team as a part of routine care.

Interviews

During the semi-structured interviews a dialogue will be developed with each participant to elicit information about their lived experience of kidney transplantation in alignment with the study's aims. Piloting with colleagues has been used to refine the key questions and to check sense, although there will be flexibility in structure as each interview will be guided by the salient issues which arise in the participants' responses.

Analysis

This study aims to build a comprehensive understanding of young people's lived experience through the kidney transplant process. Thematic analysis will be used to analyse the interview data.

Thematic analysis is a method for identifying, analysing, and reporting patterns of meaning (themes) across a data set (Braun and Clarke, 2006). Thematic analysis requires the researcher to take an active role in identifying and interpreting the important patterns/themes across their data set.

Thematic analysis has many advantages as a method of qualitative data analysis. For example it is flexible and offers a wide range of analytic options, it can usefully summarize the key features of a large body of data, it can highlight similarities and differences across the data set, it can generate unanticipated insights, and it is recognised as being accessible to researchers with little or no previous experience of qualitative methods (Braun and Clarke, 2006). Thematic analysis has been used in previous studies exploring the meaning young people attribute to their experiences of suffering from kidney disease (Wells et al., in press).

In the first stage of the analysis, two interview transcriptions will be randomly selected. Consistent with Tong et al. (2011), two reviewers (the principal researcher and their supervisor) will identify and record concepts in these transcriptions independently and discuss their initial coding choices. This process will allow the researchers to determine whether they agree upon key themes and will guide the approach taken to coding the remaining transcriptions. The remaining transcriptions will be coded by the principal researcher only consistent with Nicholas et al. (2010).

ETHICAL ISSUES

1. This study will comply with the British Psychological Society's "Code of Conduct: Ethical Principles and Guidelines" (1993).
2. Informed consent will be sought from all participants and also from the parents/carers of those who are 16 years of age or under. Prior to each interview, time will be spent explaining the study and ensuring that all participants understand that they can withdraw from the study at any time with their usual medical treatment unaffected.
3. If a participant became distressed during the course of their interview, or disclosed psychological difficulties, they would be given an information sheet to sign-post them to appropriate support services. There is an embedded renal paediatric psychology service in Yorkhill RHSC, the targeted local children's hospital. Psychological assessment and intervention would be offered by this service as required following study participation.
4. All data will be anonymised and treated as is confidential. Consistent with The Data Protection Act (1998), all data will be processed on a 'University of Glasgow' laptop encrypted to NHS standards and stored on a secure 'University of Glasgow' computer drive that can only be accessed by the research team. Audio recordings of interviews will be destroyed following transcription.
5. The study has been reviewed and approved by the 'University of Glasgow Doctorate in Clinical Psychology Training Programme' and the 'NHS Ayrshire and Arran Psychological Services Clinical Governance Research & Strategy Group'.
6. Approval will be sought from the 'NHS Greater Glasgow and Clyde Research & Development Service' and the 'NHS West of Scotland Research Ethics Service'.

HEALTH AND SAFETY

To ensure researcher safety, all interviews will be conducted in a clinical setting (Yorkhill RHSC) during normal working hours when other health professionals are in the vicinity.

PRACTICAL APPLICATIONS

This study will lead to a deeper understanding of young people's experiences across the kidney transplant process and offer greater insight into the role of pre-transplant expectations. This knowledge will be useful in improving the design of services and could also be used to develop education-based early interventions to prevent post-transplant adjustment difficulties. There are a range of potential benefits to educating young people about others' experiences as follows;

- It could enable them to give more informed consent to treatments.
- It could reduce their anxiety about unrealistic feared outcomes when awaiting their transplant.
- It could minimise the likelihood that they would develop unrealistic positive expectations which could negatively impact upon their mental health if unfulfilled by their transplant.
- It could help young people to prepare for potential problems and cope better with them when they do arise.
- It could prevent young people from feeling isolated.
- It could enhance young people's appreciation of the part they must play in caring for their transplanted kidney and reduce the likelihood of medication non-adherence.

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LAY SUMMARY

The reason for this study: Kidney failure is a life-threatening health condition that can occur at any age. One of the best treatments available is receiving a new kidney to replace the damaged one. This is called a kidney transplant. Kidney transplants do not last forever and each will eventually have to be replaced. Further medical problems can also occur after receiving a kidney transplant and these can endanger the transplanted kidney. The design of the human body means that transplanted kidneys will be rejected and lost unless people strictly take their medication.

Young people who are between 11-17 years of age are at high risk of losing their transplanted kidneys. This vulnerability is thought to be partly due to young people being less likely to take their medication. Young people are also vulnerable to developing mental health and social difficulties after their kidney transplant operations. The 'prefrontal areas' of the brain are not fully developed during adolescence. These are the parts of the brain that are needed for risk assessment, problem solving, making 'good judgments', and predicting the future consequences of current actions. Until these areas are fully developed young people are more at risk, than adults, of overlooking the long-term dangers of missing their medication. Due to their developmental stage, young people are also more likely than adults to believe that bad things only happen to others. This increases the chance that they would only expect positive outcomes after their kidney transplant operations, and leave them unprepared for the possibility of negative outcomes. Unfulfilled pre-transplant expectations could be experienced as a loss and leave young people vulnerable to mental health difficulties like depression or anxiety.

The research aims/question: This study aims to learn more about young people's experience of having had a kidney transplant, including what their expectations were before transplant surgery and whether these were fulfilled.

The potential practical implications: This study will lead to a better understanding of young people's experience of having had a kidney transplant. This understanding could be shared with other young people who are awaiting a transplant operation in order to help them prepare adequately for treatment, appreciate the importance of taking their medication, and feel less isolated. If young people's expectations of kidney transplants are better understood then any common misunderstandings could be discussed with new patients, in order that they don't suffer from unfulfilled expectations after their transplant operations. This could reduce the likelihood of them suffering from mental health difficulties after their transplants.